Bridges-Over-Barriers®

In Our Own Words

Canadian adults living with Autism and movement disorders find their voices through Supported Typing.

Bridges-Over-Barriers

In Our Own Words

Words of Bridges communicators

Edited by Andrew Bloomfield

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Bridges-Over-Barriers®
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Dedication

For the pioneers with
Facilitated Communicating and Supported Typing
who have shown the way
and given us hope by their example.

For all our families and friends
who help us on our way
and believe in our humanity.

For all donors with thanks
for your interest and generosity.

Honouring those in whose memory
gifts have been made to Bridges-Over-Barriers:
Tim's grandfather, Charles Carscallen (1906-2007),
Tim's father, Michael Marmura (1929-2009),
Andrew's grandfather, John Bloomfield (1911-2007),
Andrew's sister, Victoria Bloomfield (1968-1996).

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Introduction

I am an autistic man. I cannot speak with my voice, but through Supported Typing I have found a voice for my thoughts and dreams. I love words and even compose what my friends call poetry. I make choices about everything that affects me. For nearly seven years some of us have gathered regularly as a support group for communication. Now we hope that Bridges-Over-Barriers, through this book and DVD, will spur everyone to think more deeply about our rights and ability to communicate.

The DVD consists of two main parts—a series of conversations about the importance of Supported Typing in coping with Autism and planning our own lives, and eight participant profiles in which most of us introduce ourselves. Wonderful friends and allies have helped us to make the DVD—especially our videographer Christine Zorn. Deborah Seabrook, music therapist, composed and played the theme music. Christine also interested kind people she knows to contribute to our project. Ingrid Clark as narrator has spoken some of our words, and Andrew McPherson and Brian Ward have allowed their recording studios to be used.

This book accompanies the DVD, and is almost all in our own words. Our families and friends have supported our typing and some have spoken our words for the DVD. We are thankful to everyone who took part in the conversations at our gatherings and in making the DVD:
-Kevin Vasey with Gloria Pearson-Vasey and Jim Vasey
-Kevin Rockefeller with Judi Henry, Brenda Hofland, Michele Druitt and Beth Komito-Gottlieb
-John Morris-Dadson with Anne Morris-Dadson and Paul Morris-Dadson
-Ken Moon with Maebeth Moon and Doug Moon
-Tim Marmura with Elizabeth Marmura and Lea Tran

-Matt MacDonald with Jacquie Ferguson
-Sara Lyne with Judi Henry
-John Crawley with Tara Houser
-Andrew Bloomfield with Beth Komito-Gottlieb, David DeVidi and Jane Forgay

I dream of Bridges-Over-Barriers as a centre for friends and family who live with the challenges of Autism to come together to share support ideas and community.

Connections
Connecting is my purpose in life,
It is why we are here.
My world is connecting the dots:
You are one dot,
I am another.
We live in a world of connections,
and the lines spread out from here.
Connecting is building
a bridge of words,
a bridge of love.

Andrew Bloomfield,
Guelph, Ontario, Canada
7 November 2010

1 Our Community of Communicators

Bridges-Over-Barriers has been created by a group of friends in Ontario, Canada, most of us living with the communication and movement challenges of Autism. We use Supported Typing rather than our voices to express our thoughts, hopes and fears.

Bridges connect people and places. They allow ideas to flow and worlds to expand. Without bridges we would be isolated, voiceless and lonely. We would be uninformed and ignorant.
Bridges take many forms. They can be large, small, simple or sophisticated. Bridges have served us since early times. They are beautiful and wonderful.
Barriers are obstacles in the life of an autistic person.....
Bridge-Over-Barriers is our link to freedom and life, transporting us over the barriers of being ignored, overlooked, misunderstood and underestimated. -Kevin Vasey

The first time we met, in January 2004, was special in several ways. There were only three communicators. Tim and Joey, who already were used to typing together, came by train from Toronto to Guelph with Beth and Peter. I was host in my home with my friend Heidi and my parents Gerry and Elizabeth. Who could have known where that gathering would lead?

Since then, we have met in Guelph just about once a month between March and November each year. By August 2004, there were six of us communicators meeting regularly, with our parents and supporters—

Ken, Kevin V, John MD and John K as well as Tim and Andrew, while Matt joined us a bit later. We traveled to Guelph from a wide area--the greater Toronto area and Barrie in the east to the greater Detroit area and Petrolia in the west.

New people have come into our group and some of our pioneers have moved away. John K moved from Michigan to New Mexico in 2007, and Tim to Antigonish, Nova Scotia in 2009. Raineth who lives in France attended some gatherings in 2008 with his mother. During 2009, our numbers grew in two ways. Three members of the local ACES group came to our gatherings. We invited new friends from Norfolk-Haldimand to join us from mid-2009, with their supporters. These keen communicators include our first young woman, Sara, as well as Kevin R, John C and Nick, and still others are interested. Stephen from Barrie began to attend in late 2009, with his mother.

Several of our friends, attending their first gathering, were astounded to realize that other people use "FC" or, as we now say more exactly, "Supported Typing." They had thought they were quite alone in needing this form of communication. The gatherings are a unique part of our lives and from 2005 have inspired the vision of Bridges-Over-Barriers.

Before each gathering, I send the agenda by email to everyone, with some suggested topics for discussion. At our regular gatherings, with family members and friends, we use Supported Typing to talk about everything from spirituality to special diets. We share a meal and snacks and a walk. We view videos on topics important to us, and have shared other interests such as music, painting, our experience of nature and plants, and concerns about life transitions. We share good news, hopes

and fears. There is always time for us to mention difficulties we may be having in our lives—to share our struggles and strategies that could help.

We are thankful for everyone who makes our gatherings possible. Our parents, friends, facilitators and support workers bring us to Guelph and provide us with the physical and emotional support to express ourselves. We are fortunate to have two experienced communication facilitators, Beth and Judi, to encourage us to do our very best.

Sometimes we invite friends to join us, so that there may be 25 or more at our gatherings. As our numbers became too large for my living room, we now meet mainly at the Ignatius Jesuit Centre of Guelph, where we can use a nice big board room for our conversations, share lunch, and go for hikes in the extensive grounds. Parents and friends, who are keen to talk about all sorts of helpful topics with one another, save this for the lunch and hike breaks. So we the communicators shape the flow of discussion.

Guests and observers are welcome: we ask all to observe the Bridges protocol: *This is our message to people who would like to be guests at our gatherings. Bridges-Over-Barriers is a group that has been created by us as we grow as communicators. It is not easy for some of us, and we need our visitors to respect our efforts. Please be aware that, during our sessions, we the communicators lead the conversation and our parents and friends support, observe and record what we say.*
Supporters and visitors do not speak during the communication sessions. We hope that, if you are looking for evidence, you will see that we are a successful group of communicators. We will be happy to discuss your observations and questions during the breaks and by email afterwards.

A bridge is my image of how communicating by Supported Typing can connect my island to the mainland society and overcome my frustrations in being misunderstood and not in control of my life. These ideas were inspired by joy in working with my communication partner Beth from 2000, and strengthened by the gatherings I hosted from 2004. In midsummer 2005, I described my dream of a place of refuge and organization for communication and life planning for people who share the challenges of Autism to come together to share support, ideas and community.

By October 2005, we were using the name Bridges-Over-Barriers for our idea of helping new people to communicate effectively and thus improve their lives. I appealed to my circle of friends to understand and help me realize this vision. Guelph Services for the Autistic, a not-for-profit charitable corporation that acts as my housing trust, agreed to shelter Bridges-Over-Barriers. In the seven years to the end of 2010, we hosted about 50 gatherings and produced nine Bridges bulletins. We have a Bridges webpage on the OAARSN website.

We are producing our first Bridges-Over-Barriers DVD--all *In Our Own Words.* It shows us talking and listening to one another, and refers to our use of S-T in other parts of our lives with our families, friends and support workers. We were inspired by the video *Tapping on the Heart of the World* that was made by the Brotherhood of the Wordless in Queensland, Australia in 2005. One member of that group, Rodney, visited Guelph in May 2007 with what he called his "entourage". We had a fascinating exchange about our experiences and need for Supported Typing. It was a connection with another group of communicators and with the pioneers in Australia where what we call S-T formally began.

What does Bridges-Over-Barriers mean to me?

KM: The word bridge means something to walk across. The computer is my bridge to talk to people. The picture of a bridge means connecting with places and people. I think that a bridge is a good picture to put on a t-shirt because it tells people I want to talk with them. I cross over to meet them and we meet halfway on the bridge.
We need to support each other when we are hurt and when we are happy. I listen to the other men telling me what they are doing and I tell them what I am doing. We are great friends and we need to be together often to talk and be together.
Our Bridges movie will show people that we can talk and that we are smart. More people will see us talk to each other on our machines.

JMD: A bridge is something to help me. A barrier is something that stops me. Bridges means great, special, good friends who help in hard times.

AB: A bridge is a metaphor for connecting with others. A barrier is sometimes invisible. People's attitudes are often the worst barrier. If others think in limits about us, it is as much a barrier as cement in the road. It means the world to me that we have got close with binding ties. Bridges-Over-Barriers is important to keep ourselves and others communicating. We break some stereotypes about our empathy: we very much like to sit and talk and be together, even though people think we are not social. I don't know what I would do without our Bridges friends.

TM: This is a great bunch of people: we talk by typing and listening to each other. I like coming to Bridges and being in a good frame of mind. I like to be in this place because I can be myself-- happy and gentle. Other

people in other places put me down. Bridges does things like language and communication and is an interfaith group of very close friends, and that is the most important thing about it.

RA: A bridge that takes you from one side to the other. Bridges are made to overcome barriers like a train track or a river. In real life there could be barriers too and we overcome them with bridges which are our families and friends. Some barriers that I am trying to overcome: shyness, so I can be more independent and communicative, and able to initiate conversation.

MM: I am going over a bridge right now. I am feeling good every day. We are smart and good friends.

KR: I think it is really good here. The people are so kind and accepting. I feel loved and needed. I like being part of this group. Thanks for including me and for sharing your lives with me. This group has given me an opportunity to be a member of something. It gives me a role and that feels good. I love having people around me who understand me and like me. It is such a good feeling. I want that feeling of peace all the time.

SL: I'm glad I had the opportunity to talk. Thank you for listening. It is a big help that I can talk openly. Then I feel more proud of who I am. That has been part of being a group like being on a team. It makes you feel you belong. I belong!

JC: It is nice to be included.

KV: When I communicate with my Bridges group I feel like we've always been together and that we have a connection deeper than family. I guess we are in fact a type of family, sharing the common bond of silence in a world that is seldom silent.

A Bridges Conversation in 2007

In seven years, we have shared many thousands of words. Only a small part of all we have typed is in the DVD and this book. To illustrate how we talk together with S-T, here is part of the record of a couple of gatherings in the summer of 2007. Our leader or chair person asks the question—sometimes we may have suggested topics by email. Then we all type our thoughts at the same time, using our various keyboards and letter boards. When everyone has finished, we take turns to make our devices speak our words or our assistants read out what we typed. We may say more in reply. Our supporters also keep a record of our words—what we actually type is interesting for the way we express ourselves.

"My words and my friends help me to..." [complete sentence]
...feel good about myself.
...do the things that matter to me.
...tie together my life: my words are a bridge to my friends.
...enjoy my life better. I like talking to my friends and visiting with them.
...express myself and have a genuine social experience.

"Others like it when I do my best to..." [complete sentence]
... talk to them about my thoughts. I like it when I hear them.
...When I am happy and gentle. I like to be in this place because I can be.
Other people put me down.
...Talk and write poems.

"I like it when others..." [complete sentence]
... communicate with me using Supported Typing.

... think I am smart and able to do things. I think everyone should listen to each other and accept each other as we are.
... are good to me and in a good mood.
... hear me intensely and believe.

What strengths can you bring to a community of friends?
... My strengths are: I am smart, a great friend, happy and understanding.
... I am strong at listening, understanding and being myself.
... I am a good listener and respect other people's choices.
... I am patient and kind. I am keen to learn new things. I am understanding and ready to try new things. I am a farmer and do a good job. I am gentle with people and try to listen well. I want to visit new places. I am smart and joyful.
... I think my strengths are in my willingness to try new things. I like to host people in my home. I have a lot to say and I am good at it. I do nice things for others. I am interested in the world, close to home and far away. One strength I learned from my mother is bringing people together.

What strengths are important for people to spend more time together?
... Hearing is important.
... We should all be patient and kind. We need to wait for each other to speak. We need to pay attention to each other.
... We need to be kind, patient, understanding and tolerant. It is important to enjoy each other and have a sense of humour.
... I think being patient with each other and our supporters.
...Important to be good and kind to each other and our supporters.

What is the difference between hearing, listening and paying attention?
... Hearing, listening and paying attention are all different things. Understanding is the most important.
... Hearing is with your ears, but you may not understand. Listening is when you take it in. Pay attention, then listen.
... Hearing is listening with your heart. Listening is hearing the words and understanding them. Paying attention means focusing on the person who is talking.
... Hearing is with your ears; listening is with your heart; paying attention is using your mind.

What do you want this group to pay attention to and understand about you?
... I have bad hearing, so be kind.
... We need time alone and activities together and time to enjoy each other's company.
... I want you to understand that I like to talk and I need people to learn to communicate with me using Supported Typing.
... I think it's important they should know that I am a good person.
... I want the group to know that I am serious about Bridges and our friendship. If we live closer together we should be able to do it.

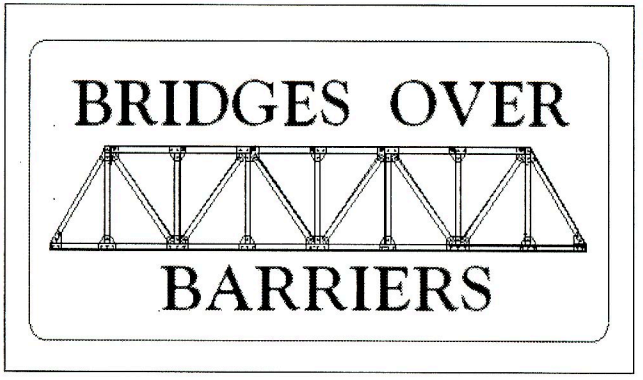
Are there any struggles you would like to talk about with friends?
... I am struggling with the people who do not use S-T with me. I need them to talk with me. I am struggling to be in control with myself. I feel tense too. I do not know why.
... You should insist. You should show your displeasure. They must understand that you need to communicate.

... I want to tell them, but they don't listen. They want me to be quiet and do nothing.
... I have to accept that people need to support me. I have to be patient with the people that help me. I think learning new things takes time and patience.
... I am struggling with myself, and how to be with others when I get upset. I do not like it when I lose it but I cannot help it. It is hard to control myself and not know what it is about.
... Can you take a break from people? Think calm thoughts and say a prayer.
... I am struggling with the idea of never being independent. Who will do interesting things with me when my parents are gone?
... I think we all struggle with this. That's why friends, and circles and Aroha are important.
... I am struggling really hard to wear the hearing aid because it hurts to hear.
... You are doing very well. You are my idea of a good man.
... I think it will improve as time goes by. Keep it on a bit more each day.

How do we find good friends?
...I don't know. Who will be friends with me? I am different. People feel afraid of me.
...I think they are just there and we find them as we go along.
...I think friends make new friends, not by ads in the paper. We are friends here and more are coming.
...This is where we need our family to intervene. I think the Bridges group should publicize itself so that more people get involved in Supported Typing.

Andrew Foster, our friend who is an engineer and miniature bridge designer, made a model bridge to be a kind of mascot for Bridges-Over-Barriers. Andrew is a trustee for Bridges on the board of directors of Guelph Services for the Autistic which administers our funds. He also composed these words about how he sees our Bridges support group:

A bridge lets you reach across a barrier to a place where you couldn't go before. But Bridges-Over-Barriers isn't something that other people have built for you, like the keyboard that you use; it isn't something you can buy in a store, and in fact, it isn't a 'thing' at all. You are the bridge, you have built it, and it can't exist without you. Like a bridge made of metal or wood or stone, each part plays an important role in the structure; it depends on each of its parts for its strength. Perhaps the miniature bridge will remind us of the strong structure that a small group of determined people, working together, can build. It stands on the strong foundations of families and other supporters, but, like the metal struts and the rivets that work together, it's the Bridges people themselves who are the structure that reaches across the communication barrier.



2 *Recognizing Our Needs to Express Ourselves and Our Rights to be Heard*

In this chapter, we tell you why and how we communicate in our way, using AAC (Augmentative and Alternative Communication) aids and methods. We want everyone to understand that it is we who are doing the thinking, pointing and spelling, while our supporters steady our hands and muscles, so we can express what we really think and mean.

We call our way Supported Typing (or S-T) which is a more exact term for what we do, as we use keyboards or letter boards to type words and sentences. Most of us were first introduced to this way of expressing ourselves as a form of "FC" or Facilitated Communicating which can also include pointing to pictures, symbols or words. "FC" has been sadly misunderstood and even condemned by various kinds of people in authority. People who do not understand how we express ourselves may also dismiss it. We want everyone to have the rights and opportunities to express themselves, in whatever way works for them. For us, using the term Supported Typing (or S-T) is good—both in being more precise and in sidestepping controversies and misunderstandings about "FC".

Supported Typing is a bridge for people who cannot speak reliably with our voices. Supported Typing is not a cure for Autism but our bridge to the world. I remember the first time I used S-T, when I spoke for the first time in words that made sense. The bridge took me from the island to the mainland. When I learned to communicate in a new way, using Supported Typing, I had a whole new world open. Now I have a way of communicating and, though I am still autistic, life is better.

Why Supported Typing?

What we call Supported Typing is a method of Augmentative and Alternative Communication (AAC) that enables us to understand and make choices about our lives as other people do. We have neurological disorders that affect all our movements including those of our vocal chords, so we cannot speak reliably with our voices. With the right kind of support, we can co-ordinate our movements better and type our thoughts and feelings in words that other people understand.

Once we have been assessed as having the potential, we may be matched with communication assistant(s) who provide varying degrees of physical support, as well as environmental and emotional support, so we can type letters and words on some kind of communication aid. Such aids range from simple boards with numbers and alphabet letters to computerized devices with voice, display and printed output.

In the most common method, the assistant provides physical support in the form of backward pressure so the communicator focuses on reaching forward to touch or type on the device. The form of support required varies with each person and has been likened to learning to dance together. For some people, a touch on the shoulder may be enough; others may need help in isolating the index finger with which they point to letters or press the keyboard. The amount of support we need may vary at different times, depending on our state of health or level of anxiety or on whether the environment is distracting us. Some of us who have been fortunate to reach expertise and resources have been able to develop independence in typing, and to continue in literacy and further education programs, and a few have graduated from college.

For most of us in North America, Supported Typing developed within the larger context of Facilitated Communication (FC) which also includes physical support to help people point to objects, pictorial symbols, photographs or words. FC techniques attracted much publicity in the early 1990s, but then suffered a backlash of misunderstanding that has hurt FC and FC users.

We prefer the term "Supported Typing" for the form of augmentative communication that we use and are trying to encourage through Bridges. It is better for us, for these reasons:

1. Supported Typing describes more precisely what we do. We distinguish the thoughts and language in our minds from the physical actions of actually expressing these in ways that other people can understand by typing on a letter board or electronic device that has a Qwerty keyboard. While we cannot reliably express ourselves with our voices, we can read and know how to spell and what words mean. We have language and are literate. We also want to make ourselves understood. Our neuro-motordifferences mean that we need support to get our meaning out in ways that can be read and heard by others.

2. ***We focus on the physical, environmental and interactive support*** that we, as people with severe neurological and movement differences, may need to steady our hands and brains to type. Physical support includes "backward resistance" by our assistant steadying or pulling back our typing hand between each keystroke--so that our nerves and muscles don't just continue randomly and we have time to choose which key to hit next. We also need to have our environments

arranged so we feel relaxed enough to focus on what we want to type. And we each need a positive relationship with our communication partners or assistants who listen to us and believe that we have something worthwhile to say.

3. ***Supported Typing is a more specific form of AAC*** while Facilitated Communication means a wider range of augmentative communication strategies by people without functional speech who augment their speech by using communication aids with their hands. This may include pointing to picture symbols or words or the use of abbreviations.

4. ***We may avoid the misunderstanding and negative perceptions*** that resulted from the controversy about "FC" in the mid-1990s. Educators, professionals and administrators became so nervous that they seemed to abandon efforts to encourage communication by people who do not speak (especially people with Autism). By using a different term, which is also more exact, we may sidestep the controversy and help people who could really benefit.

We who use Supported Typing in Bridges-Over-Barriers know that "FC" has been controversial. Our way of talking is so important and enabling for us that it's hard to understand how some people may be sceptical or even hostile. But we also meet other people who have never heard of a controversy and are more open-minded. We hope that our DVD film and this book will help people to have a more balanced view and to welcome communication strategies that enable us to express our thoughts, lead our own lives, and be included in our communities.

A little history ...

We know that a few autistic people without voices had shown they were able to write or type with support in the 1960s and 1970s. Rosalind Oppenheim described supported handwriting in Chicago from before 1970. A young Ottawa man, David Eastham, used supported typing on a memowriter device to compose poems through the 1980s: they were published in two books. Nobel laureate Arthur Schawlow used similar methods with his autistic son in the early 1980s and felt that they were helpful. But few knew about these pioneers.

Facilitated Communication (also known as Facilitated Communication Training) became more widely known only with the publication in 1980 of *Annie's Coming Out* by Dr Rosemary Crossley with Anne McDonald, one of her patients with cerebral palsy in an institution in Victoria, Australia. In her legal struggle to direct her own life, Anne was a brave pioneer, leaving the hospital after successfully fighting an action in the Supreme Court of Victoria. Crossley has continued her efforts in the DEAL Communication Centre in Victoria and in traveling the world to present workshops. As well as various manuals and guides about FCT, Crossley also published *Speechless* in 1997. Jane Remington-Gurney, a speech language pathologist who trained with Crossley, has practiced and taught FCT in Queensland, Australia for nearly 20 years and now directs the Options Communication and Therapy Centre there. She has also published various guides to AAC.

Facilitated Communication reached North America after the return from a research visit to Australia by Dr Douglas Biklen of Syracuse University.

He began advocating use of FC methods in January 1990 and published a widely read article about his findings in August 1990 in the *Harvard Educational Review*. Now Dean of Education at Syracuse, Biklen has continued to encourage and publish on research and best practices.

News of Facilitated Communication spread quickly around the networks of professional and service organizations in North America in 1990-1. In the early months and years, there was huge enthusiasm for the idea that FC might be the key to unlock expressive communication in children and adults who had not been able to speak because of their Autism. There were astonishing reports of people, presumed to be severely intellectually disabled, being able to spell out complex messages. Most of us shared in this marvelous mood of liberation.

Some of us were introduced to FC by professionals in speech and language who knew what they were doing. They explained something of how FC might be working for us. They were careful to confirm what we were saying by asking the same questions other ways. It wasn't physically or emotionally easy for us, after being unable to make ourselves understood for up to 20 years or longer. For me it was worth the pain to speak for the first time in words that made sense and to know I could spell and read, and that other people saw it too. I saw what joy it gave my parents, sister and friends to "hear my voice".

However, FC was perhaps too easily accepted as a low-cost response to what were perceived as very serious disorders. At that time most people with Autism were seen as very seriously impaired with no hopeful interventions or positive outcomes. In 1991, Autism was being diagnosed in a much smaller proportion of the population than Autism Spectrum

Disorders are now found in 2010. It was seen as a psychiatric disorder with three main areas of impairment—communication, socialization, and attachment to order and routines. The prevalence of "classic" Autism then was about 4.5 per 10,000—more or less what would be officially defined as Autistic Disorder by the *Diagnostic and Statistical Manual of Mental Disorders* (1994 edition). In addition, more people might be diagnosed with Pervasive Developmental Disorders (PDD), which together with the classic Autism made up a total prevalence rate of 21 per 10,000. (By 2010, studies of the prevalence of Autism Spectrum Disorders were finding that they affected about one per cent of the population, at the same rate in adults as in children, and with about half of the total having Asperger's Syndrome).

A general Autism survey was taken for Autism Ontario in 1990-1, just before the news of FC broke. Of the 802 adults with Autism found by the survey, almost half were reported to be non-verbal and 30 per cent had no augmentative system that they could use for daily needs. Responses to a question about "estimated IQ level" pegged over three-quarters of the total at 70 or under, with fewer than 6 per cent at 85 or higher. These were assumptions rather than measurements, as autistic people were generally regarded as untestable and incapable of being educated or trained. In addition 21 per cent were reported to have seizure disorders, and 28 per cent to have additional "mental" disorders (such as "manic, bipolar, schizophrenia, depression, anxiety"), and 44 per cent were reported to have "severe behaviour problems." Nearly one in four combined at least two of seizure, psychiatric and behaviour disorders. These survey data are quoted, not because they represent the full truth of our challenges, but to suggest how people with Autism were viewed at the time FC was introduced.

What did most people assume about Autism in the early 1990s? Psychiatrists and psychologists were the professionals who were supposed to know about Autism. Some of their attitudes carried over the earlier equation of Autism with childhood schizophrenia, an incurable mental illness which, it was usually implied, had been caused by the parents. The approach was pathological—diagnosing what's wrong. Most speech language pathologists also had this approach: they were not speech therapists. Such professionals were very rarely concerned with constructive interventions that looked for and encouraged abilities. Someone who could not speak tended to be dismissed as nonverbal and incapable of understanding or rational thought.

In the early 1990s, FC offered hope of some improvement for adults and children with Autism. Some were able to break out of their isolation and to show clearly that "though we cannot speak, we have things to say".

Educational and social services readily took up FC as an easy strategy for everyone who didn't speak. There was such a demand that people tended to be drawn in to act as facilitators before they had time to learn the theory about how FC worked or best practices to ensure the reliability of what was communicated. Willing people with no particular training or experience were pressed into service to support a communicator's arm, wrist or index finger.

It is not surprising that the enthusiastic adoption of FC provoked controversy and backlash. Some detractors could not believe that people with Autism could think or had language or anything meaningful to say. Some sceptics organized research projects to test the competence of communicators, their hypothesis being that the facilitator, perhaps

What everyone yearns for-- really good support to communicate....

Supported Typing is so liberating. I was locked before it. I had to hope others would see my intelligence in my eyes and behaviour, but these were not reliable. I saw that nobody really knew how smart I was. I had no way to express myself apart from some signs and pointing. People had to guess what I wanted and needed. It was so limiting. I was impeded by my movement disturbances. I might get things I needed, but couldn't say what I thought and felt.

I think other people saw a primitive childlike person who was not a thinker. I know it is hard to respect someone who paces and screeches, but says nothing intelligent. People did not know that I was trying to be in control of my body, when my body went in the opposite way from the way I wanted. I tried to keep calm, even though I got upset. People only saw my racing and pacing. Not my inner struggle, and that I was really working to hold in the storm. It felt like I was observing my own life but not controlling it.

When others did not understand me, I was sad and frustrated and agitated all the time. I got angry. I was hopeless: I never expected to find a better way. A few people really looked inside and past my Autism. Until Supported Typing I did not know I thought in words that others could understand; I was just absorbing their words.

I remember the first time I used S-T. It was with M--. I trusted her and let her show me pictures and ask questions. I pointed to and typed the right words. I spoke for the first time in words that made sense. I was very surprised by S-T. Now I knew I could spell and read, and other people saw it too. Now I had thoughts. Now I could talk.

unconsciously, was the real author of the message. However, the laboratory settings used in these experiments were unfamiliar and the "facilitators" were new to the "communicators" and did not provide explanation or emotional support or techniques like backward resistance. Negative reports of these experiments began to be published in 1993.

Advocates of FC responded with critiques of the research methods used and with qualitative studies that were more sensitive to this mode of communication. Qualitative and controlled studies showed that FC is useful for some individuals, but also that some facilitators may influence what some communicators type. Some studies concluded that the validity and reliability of FC were not established. There was debate over whether quantitative (controlled) or qualitative (ethnographic) methodologies are most appropriate for the study of human social interaction, communication in general, and FC in particular. The largest quantitative validation study reports that, under controlled conditions, some FC users can pass information to a facilitator when that facilitator is not privy to the information. A critical factor in studies with positive outcomes is that communicators had prior practice sessions in message passing (where a person reveals information that others can verify but which was not known to the facilitator). Thus they knew in advance the rules of the experiment, rather than being taken by surprise.

We may think now that not enough attention was given to some basic technical competence and best practices or to working out a theoretical basis to explain why FC worked so well with at least some people with Autism. There might have been more attention to detecting which kinds of people with Autism might seem most likely to respond.

Proponents of FC did not describe critical elements of technique clearly enough—notably the need to provide explanation and emotional support to people being invited to communicate with support, or the need for backward resistance. People who facilitated were not trained carefully enough in these techniques or the need to verify statements that seemed surprising. A survey of FC and validation tests is presented in Biklen and Cardinal's *Contested Words, Contested Science* (1997).

A more sensational problem surfaced after some support workers interpreted literally statements by communicators that seemed to allege abuse by their caregivers. Some allegations were later proven but some were unfounded. Caregivers and parents in the US (and also Canada) were naturally upset by police inquiries. Some went public and sued the agencies and institutions that had allowed FC to be used with their children. Studies denying the validity of communicators' statements were quoted far more often than stories of the success of FC.

The validation controversy and news of the abuse allegations made for very negative publicity, especially following the PBS Frontline show in October 1993. Threats of lawsuits against agencies, school boards and communication professionals led to defensive reactions that made it very hard for autistic people who do not speak to get expert help with any communication modes. Agency administrators who had previously encouraged FC took fright and banned any such support. Speech language pathologists' colleges did likewise. In Ontario for example, the College of Audiologists and Speech Language Pathologists (CASLPO) followed the example of its US counterpart ASHA and forbade its members to consult to and advise people about FC. Some exceptions were later allowed where persons and families signed waivers.

Communicators and their families were on their own, helped by a very few dedicated facilitators who were not members of professional colleges. We can only guess how many people with Autism started to communicate using FC in the earlier 1990s but were then prevented from continuing. Almost all of us were left without any reliable form of communication. A few of us were lucky to have parents, friends or supporters who realized how important S-T is to one's sense of being a thinking person who is connected with one's community. But we had only fragmented and irregular support to express ourselves.

It was a hard shock for us to realize that "FC" seemed at best to be controversial, after all the joy and enthusiasm surrounding us when we began typing to talk in the early 1990s. I did not understand why the change, but I could feel the difference in people's attitudes. Most of us who were supported in some way by large organizations--agencies, facilities or school boards--were denied any help with the form of communication that was most reliable for us. One Bridges man was lucky when his mother persuaded his school board to allow his educational assistant to continue supporting his typing. And a few of us have been able to get communication devices prescribed for us, if we didn't mention our Autism diagnosis, just that we need devices with voices because we cannot speak with our own.

For autistic people in Canada with severe communication impairments, little has changed officially since the mid-1990s. It has seemed that the wider definition of Autism Spectrum Disorders during this period, and the focus on the much larger numbers of young children who were identified with ASD, have meant that adults with the most complex challenges of Autistic Disorder have been overlooked.

In 2010 we may see some reasons for hope. Attitudes may be shifting in relation to the form of AAC that we call Supported Typing. Factors include the movement for disability rights including the basic human right to communicate; the demonstrated success of various communicators who type to talk because they cannot speak with their voices; and some rethinking by professionals of both the nature of Autism and the mode of communication that we call FC or S-T.

During the past 20 years, movements for general disability rights have flourished and have explicitly included the right to communicate. Recognizing the rights and abilities of people with Autism has been slower, however. We mention some of the organizations and advocacy that have helped us to keep going.

The Autism National Committee, founded in 1990, carried a lonely torch for North American communicators with Autism when we had few allies. AUTCOM is the only Autism advocacy organization that has consistently declared support for FC as part of its dedication to "Social Justice for All Citizens with Autism" and its commitment to positive approaches. Its policy, restated in 2008, is "that everyone has something to say and a right to say it. Facilitated Communication is one accepted and valid way in which individuals with Autism can exercise their right to say what they have to say." With its journal, *The Communicator*, AUTCOM is dedicated to "protecting and advancing the human rights and civil rights of all persons with Autism, including access to state-of-the-art communication options for all with unique communicative and social needs." The theme of its 2010 conference was "Communication, Competence, Community: Nothing About Us Without Us!"

AUTCOM upheld the principle of the Presumption of Competence as the least dangerous assumption, first proposed by Dr Anne Donnellan in 1984. Another paradigm shift for persons with Autism who were generally regarded as being severely intellectually handicapped and incapable of rational thoughts is the understanding of Autism as a neurological condition with neuro-motor and sensory impairments. We discuss this in Chapter 3 with Martha Leary who has supported many of us in our communication journey.

THE COMMUNICATION BILL OF RIGHTS

I have the right:

-to express feelings and needs
-to be listened to with respect
-to understand communications
-to request information
-to have access to information
-to learn about myself
-to learn about life
-to aids, services and resources
-to be included in social interaction
-to be offered choices
-to reject

Based on original models by American Speech-Language and Hearing Association (ASHA) and Compic Scope in Victoria, Australia.

Movements for general disability rights are gradually helping to shift attitudes to people with Autism with severe communication impairments. In the US a Communication Bill of Rights was put forth in 1992 by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities of the American Speech-Language and Hearing Association (ASHA).

TASH (originally The Association for the Severely Handicapped) used a grant from the Nancy Lurie Marks Foundation from 2002 for the

Breaking the Barriers project that advocated for communication rights, including those of persons with Autism, and acceptance of FC in practice and policy as a legitimate mode of AAC.

Professionals engaged in Augmentative and Alternative Communication (AAC) are also advocating and helping to implement general communication rights—nationally and internationally. ISAAC, the International Society for AAC, has Chapters in 15 countries as well as members in 60 other countries and envisions a world in which everyone who could communicate more easily by using Augmentative and Alternative Communication (AAC) will be able to do so. ISAAC members include people with Autism who use AAC and professionals who work with them, and their issues are covered in conferences and publications. In Canada, Augmentative Communication Community Partnerships-Canada (ACCPC) is a federal, non-profit organization that undertakes social innovation projects to promote awareness, justice, enhanced quality of life and community participation for people who use AAC. It is devoted to implementing communication rights in our communities.

We have been encouraged by the published successes of some brave pioneers. Most have been associated with the centres of expertise in Australia (around Crossley's DEAL Communication Institute) and the United States (around the FC Institute founded by Biklen of Syracuse University). These leaders have continued their influential roles in training and promoting best practices. Professionals with training and experience in these centres have established nodes of support for FC elsewhere in their countries. Thus Jane Remington-Gurney, a speech-language pathologist who trained with Crossley, now directs the Options Communication Therapy and Training Centre in Queensland, Australia.

Syracuse has maintained regular conferences and workshops for communicators and their facilitators and supporters all over the United States. The Yahoo group "FCworld" with 300 members offers a "safe place to discuss and share information about FC worldwide".

Communicators with FC who have persevered to become virtually independent typers and those who have even developed limited powers of speech inspire us with hope. Early books by successful communicators were *Beyond the Silence: My Life, the World and Autism* (2000) by Tito Rajarshi Mukhopadhyay of India and *Lucy's Story* (2001) by Lucy Blackman of Australia. North American success stories in film include Jamie Burke in *Inside the Edge: A Journey to Using Speech Through Typing* (2002), Sue Rubin in *Autism is a World* (a 2004 Academy Award nominee) and Larry Bissonnette in *My Classic Life as an Artist* (2005). These five communicators are also featured in the volume *Autism and the Myth of the Person Alone* (2005) which includes essays by them as well as their conversations with Douglas Biklen as editor. The other two are Richard Attfield of England and Alberto Frugone of Italy.

Among a few other books and films by successful communicators, we are proud of Kevin Vasey, a Bridges member who co-authored *The Road Trip: Life with Autism* (2005), with his mother, Gloria Pearson-Vasey. It is a most thoughtful account of Kevin's use of FC and the importance of communication in his life since 1992. The book is organized thematically, with chapters on Communication, Community, Adjusting, Addiction, Resources, Relationships, Hope and Dreams, Limitations, Pioneers and Pilgrims, The Quest for Meaning, Going Home, The Advocates, Confronting Rejection and Loneliness, and Pilgrims' Process.

The way ahead is still not clear or easy for people who type to talk because of their severe Autism and inability to speak with their voices, especially in Canada. But there are some signs of hope that other people are getting the message.

More observers are noting that adults with Autism are judged more severely than any other groups of people who cannot speak with their voices. Why are adults with severe Autism and complex communication needs required to prove themselves and perform at higher standards than anyone else? Other people with disabilities use communication aids and have human assistance without everyone disbelieving them. We dream of the day when people will be astounded that we were so excluded and isolated because we cannot speak.

There are many myths about Autism and our way of communicating. One myth is that Supported Typing (what we used to call FC) is easy. It is not! But it is all we have.... In the words of Rosemary Crossley, feisty professional and advocate in Australia where the story of FC/FCT began:

> *Facilitation is a last resort...Facilitated communication is difficult, limiting, time-consuming, and controversial. If you can find any other halfway satisfactory way to communicate with a person, jump at it. If you can't, try FCT – and try to work your way out of it as soon as is feasible. A few people find that after a year or two of FC they can get a bit of speech back. Others find that with sufficient practice they can learn to use communication devices without assistance. Some people find they can work independently some of the time but revert to dependence when under stress. ...In any case, the decision is theirs.*

Facilitated communication is the worst possible way to communicate. If you can't make any other way work, though, it's being recalled to life. Do what you like - but remember what's important.

What is it like, not being able to rely on our voices?

KV: It was a terrible thing to be present and yet invisible and considered stupid and unaware of what people were saying. I felt lonely, trapped and scared.

KM: Before S-T, I did not talk and people did not know what I thought. I felt sad, frustrated and angry because I couldn't share my ideas and thoughts and I felt unhappy not to speak like other people.

SL: I get insecure when I can't communicate with people.

AB: Before Supported Typing, I had ways that were just for basic needs or pointing to something. That was not always reliable. I would sign No when I might mean Yes or Maybe.

TM: The hardest thing was not having a facilitator all the time. I had things to say but no one to listen. I felt that I was in a hell of a place and I did not hope to get out.

What difference does Supported Typing make?

KV: I can express myself and have a genuine social experience. Communication makes us feel spiritual and caring. It is a wonderful thing to be able to express our thoughts and feelings and to be respected by

others. Also you can ask other people how they are feeling. It is definitely better with others who use Supported Typing. When I am with those who speak, I am ignored or treated as if I were not a person. People have to understand that it takes patience and perseverance for us to explain ourselves, and that signs and symbols don't cut it. ...It's difficult just being autistic. S-T marks the difference between hell and life.

AB: I know what you mean, Kevin... It is a heavenly gift to have S-T. It is the way we get in touch with our feelings and each other. I think it is opening my mind to let others inside to know me and what I think and believe and feel. It is as if the more I communicate the more I think. It opens doors to our inside thoughts so that we can interact--the world can understand me and I have a chance to be in the world. I mean out in the world as I am who I am. I want to tell my friends how good I feel when I can say what is in my mind. S-T gave me respect from others. I have a way of communicating and though I am still autistic, life is better.

JMD: My words and my friends help me to feel good about myself.

JK: S-T is my chance to talk to the world.

KM: I feel wonderful to be able to talk to my friends and to share my thoughts, ideas and needs. My parents and supporters need to know what I think and feel. Communication is talking and listening. Communication is a great way to visit with people and find out what they have been doing and how they are feeling about things.

TM: It is extremely important, to speak and not be ignored. It is the way we put things in words or in our minds and then feel them and say them. I am glad that I can use this board and I am going to use it more in the future.

KR: It is really important. If I don't have the ability to S-T, I get mad and stuff happens that is not my fault (all of it).

JC: S-T is important to me because I can tell people what I want. Sometimes I want to yell at the world and I get frustrated when I can't tell people what I feel. I like talking and I need to talk more, but I take a long time to talk. It is real hard; I need to focus, and I need more time. I like talking to people about my life. I need to tell more so I don't get misunderstood. It happens. S-T is real to me. I need to use it, but I am stubborn; I get in my own way and I make my own choice. I like S-T; people believe me and I feel important when I say what I need.

3 What It's Like To Live With Autism: Understanding our Movement Differences

Martha Leary is a Speech Pathologist and Communication Consultant with an international practice, and an author and presenter at workshops and conferences. Now based in Nova Scotia, she lived for many years in Toronto where she was with The Geneva Centre for Autism. Martha introduced several of us to communication in various modes, and to FC in the 1990s. A good friend of Bridges, Martha has known several of us for 35 years. When we asked her to write a piece for Bridges in 2006, Martha suggested that this could be based on emailed interviews with our group. She asked questions, to which we replied. We asked Martha some further questions. Here is the transcript of this exchange of ideas. Martha's term "movement and sensory differences" includes what we call being "stuck" and "hyper—unable to stop".

What it's like to be me
I'm a bundle of sensations:
I get the urge
to touch and pick
and I must follow my urges.

Can you see my urges?
I can't tell you:
I just show you.
I'm a bundle of nerves
and a jumble of thoughts.
I'm in constant motion
and my mind's always going.

I wonder what it's like to be you.
Do you wonder what it's like to be me?
I'm a time bomb waiting to explode
and a tear waiting to fall.

Martha asked us: Are there times when you want to do something for yourself and you have difficulty getting started? What kinds of situations cause the most difficulty for you in getting started? What do you feel like when this happens?

KV: I feel that being stuck is the worst part of being autistic and it's what stops me from having a normal life. All the time. Getting dressed. So frustrating. People ... say I'm lazy because they do not understand. I get angry and want to lash out but I've learned to be patient and keep it inside. I am affected by other people's moods. I like calm sounds....

JMD: Yes I really get stuck sometimes. Undress, going to bathroom, to bed. Feel depressed.

TM: I don't know why I have hard times but I wish I could get over them and be normal. I think it is because of things both inside and outside my body. I don't understand what is happening inside. I would like to know what makes me so anxious and upset. I don't know how to control my compulsions. I do not like it when I lose it but I cannot help it. It is hard to control myself and not know what it is about.

KM. I am always in motion because I feel restless and can't stop moving because I feel movement inside my body and I don't know what to do about it. It is very hard for me to accept changes. I need help to keep going because I get stuck and cannot move. I have difficulty getting started when I want to stand up or sit down or want to eat food. I feel stuck and frustrated when I try to do things and I want help to set started and to finish my action.

AB: Our lives are challenged by not controlling our movements. Being stuck in our bodies. I know about being stuck. This past summer I was more stuck than for a long time. I feel like I could explode. I do feel that my body is not in sync. I am just wired. It feels like I am not in control of my body, so my mind is telling me one thing and I do something else. I cannot participate in life.

When I want to do something and am stuck, I feel helpless and sad but sort of resigned. It is not the kind of situation for me--it is how my body is at the time. When stuck, I usually show it by my hands clasped over my ears. I feel pain in my ears because it is emotionally taxing. Holding my hands over my ears gives me a feeling of control and some comfort. It keeps the storm in.

When I am stuck I cannot bear to get much information from others. It is internal. I have to cope with my body freezing, so I cannot take more stimuli.

MM: Barriers are too great, too many, go over and under. Try to understand.

JK: I do sometimes [intend something] in my head and my body doesn't do it. It happens all the time. I have difficulty at my school. I get stuck if I am not familiar with it. Like if the teacher changes the order of things. I feel like an angry bull who cannot get started.

What about when we know what to do but can't get our body and muscles to co-operate?

AB: I can be very agitated. It is very hard to communicate when our bodies are uptight. I like to talk and be listened to. I still try to type when

I am stuck. I focus when I get started. I start to type and my ideas come to me. I will try harder when I am stuck. My weighted blanket in the Relaxation Room, music and walking are my anxiety medicine.

TM: I think that if people are in tune with us that they could help us more.

KM: I need to be asked. Remind me often to talk to find out what I want.

How do we get other people's attention to help us when we are stuck?

AB: How can we show others if we need help. I need ideas to get attention in a social way. Or I can get excited.

KM: I take Mom's hand and I touch the computer for Mom to get ready for me. I also point to things when I want help. I go to the workers and bring them to what I want to do. I look at people and they look at me to see if they can help me. I need to be reminded to look at the board and to look at people's eyes when I am out in social situations. I need help to be with people by doing a story first about the visit.

TM: When we need flexibility but don't have it, we get agitated. I am struggling with myself, and how to be with others when I get upset. When people are hard on me, this makes it worse. I think they are being mad and severe in their judgments. We need people to hear us. I need people to help by being there for me. It is important to give support workers time to know us.

KV: They should tell me to use the computer and I tell them what I want. One night I was awake with a migraine, but nobody asked what was

wrong. It would help if we were in the room together and we could practice to be ready.

AB: I like the ideas of role playing and the social story. I need help reading people's faces and understanding how they feel about things.

KV: I need a mirror to see what my face looks like. People get confused by my body language and facial expressions. If you look in a mirror, you will see angry, smiling, happy. I recognize other people's facial expressions, but not my own.

What helps us to move when we feel stuck?

JK: It helps if I think about what it is that I want to do and then I do it. [Picture yourself doing it?] Yes.

JMD: I think I need a real polite push. Like when D-- stood behind me and held my hands, then I could push the wheelbarrow at the farm.

KM: I need help from Mom and Dad when I'm stuck. Yes, touch helps. And counting too. And I like talking from support people [but softly and not repeated].

KV: Of course yelling at me is not the answer. I think we need sufficient time. Sometimes words are best. Other times a touch helps. [Counting?] Yes, my mom does it all the time. A soft firm touch done with kindness. Touch is good if it is gentle and friendly. If it is pushy I would rather have an angry voice.

KM: I can be helped with a soft touch too.

JK: Counting annoys me [an impatient testing tone is different from a supportive one]

AB: Get me to visualize. Someone should say: "Imagine you are doing the activity, not thinking about being stuck or moving." Bouncing and rocking can get me out of a stuck place.

How can other people recognize our difficulty and provide the assistance we need?

KV: They should know that I am not being difficult. I am not a child. They should ask me and make sure I know what they want. When I say yes, they should be more patient.

KM: They can tell by my blank stare. I think they can ask if I'm stuck and I will tell them if I am stuck.

JMD: Here [Bridges gathering] freedom from very great hassle. I need a person who uses S-T to understand me.

JK: [People think you're being stubborn and non-compliant?] I think that they do not understand. I think it helps me if they are kind to me. It also helps if they are a good friend.

KV: Maybe John is saying he doesn't like being bugged when he knows what to do.

AB: I will say No in many ways. So keep trying in many ways. Don't give up till you try many ways. When I am stuck, I am helped to move and do my action if E lightly touches my elbow or the small of my back. Or she may sign. Then just wait a few seconds, and I will do it. That is better than telling me what to do when I know it. Someone can facilitate our movements when we are stuck, like facilitating our communication. When this happens, I want people to try to help unless I stop them. If I

stay, it is a sign that I don't want to quit. Today I am stuck and I notice that Beth keeps handing me a magazine and then takes my typing hand while it is away from my ear. This is smart. I need my friends to keep trying and to think of smart ways to help me keep going.

We have times of being "hyper", restless, always in motion, unable to stop our movements. Does everyone have these impulses? How do we cope?

AB: I'm still a bundle of sensations. I feel I have to keep moving. People should know that it is always a struggle, even when there is no outward sign. We all lose it sometimes in different ways. I get hyper, run, scream and clap if it is bad. Don't worry if you lose it when we are together. I have to control myself if others lose it. But I don't want them to feel bad.

TM: I feel like that all the time. I do not know what to do when I am like that and I do not think I can stop. I try to stop. I am not stopped. It helps to be calm and not get angry with me and not to put me down. People kind and calm. S-T has helped a lot but the obsessions are still strong,

JK: I hate it. It is the worst thing in my life. My dad helps me in those times. He is kind to me in those times and every day. Swings help sometimes. Another thing for me is I am not so happy when people say I can't do things my way.

KM: I am always in motion because I feel restless and can't stop moving because I feel movement inside my body and I don't know what to do about it. You can stop me by holding me still and getting me to think about something else instead of moving about all the time.

JMD: All the time.

KV: Of course it is the worst part of being autistic. [Addiction] is like a demon in my head. I am affected by other people's moods. I like calm sounds like in the woods.

What happens if someone tries to stop us when we are hyper?

AB: I think that I just go right through them if they get in my way. [Because you cannot stop?] It is because I have to do it ...

KV: I am not stopped. I need a reminder. We try to look normal but need help. [What kind of reminder?] Saying "hands" [a cue not a lecture]

JMD: I feel mad. Yes, hold hand.

JK: I think it's extra bad because I start to get mad and defend myself in school. Another thing for me is I am not so happy when people say I can't do things my way. [Everyone agreed that others may not like our passion to tidy or rearrange things, especially in the kitchen]. The world needs autistic people to keep it tidy!

How other people see our sensory and movement differences and the connections with communication. Why do they not realize that we are smart?

Martha: You have a good point John. I find that when people move differently and organize their actions and communication in unique, sometimes unconventional ways, other people are often puzzled. If a

person does not respond in expected ways, some people assume the person has a general incompetence. Often this results in further isolation for the person and fewer opportunities for meaningful social relationships, appropriate education or employment.

Martha, what pointers can you come up with for us?

Martha: Kevin, I am learning more every day. I am learning from the experiences of people like you. I do not have adequate answers to explain people's experiences. I have spent time gathering people's stories and sharing them. I hope to help people to begin to understand the concept that sensory and movement differences can mask people's competencies. I recently co-wrote a chapter for a book called *Stress and Coping in Autism,* introducing a person's point of view on sensory and movement differences.

Martha, why do we get stuck? What is not working right in our brains? I am stuck only sometimes. Why do I have such extremes from fluid to stuck? Why only sometimes?

Martha: Andrew, you ask very good questions about what is causing you to get stuck. I do not have an answer. I can tell you that your description of the extremes of fluid and stuck is much like the experiences of other people with movement differences. In the future, I would like to share with you some of the things I am learning about how people are able to 'accommodate' to some of their sensory and movement differences.

Martha, what is the connection between being unable to move sometimes and not being able to speak with our voices? It is very hard to communicate at all when our bodies are uptight.

Martha: Speaking is the result of some very complex cooperation among various systems of the body. Sensory and movement differences may affect each person differently. For many people with Autism, any use of the voice is challenging, others may use the words that others have said (echolalia), but experience difficulties generating spontaneous speech. Temple Grandin, a person with Autism who is quite able to speak, describes some of her speech challenges in the film, *A is for Autism*: "I cannot follow the rhythmic give and take of conversation. People have told me that I often interrupt and I still have difficulty determining where the pauses are."

Consider the body systems involved in speaking: free movement of the jaw; agility of the tongue; well coordinated, effective breath control; moving at the right time; coordinating the movements of these different systems; using facial expressions and gestures that match the meaning of what is said; using the vocal mechanism – 'voice box' or vocal folds – with the right amount of force and pitch; keeping the rhythm of a conversation by taking a turn after your partner speaks, and so on. When sensory feedback and reliable movement are compromised, any of these systems can be affected.

In the literature on movement 'disturbances', there is frequent reference to 'muteness' as a symptom. This can happen to people with Parkinson's

Disease or classical Catatonia, as well as to people labeled with Autism. For some, muteness is temporary or intermittent. For others, muteness is a constant in their lives. The actual mechanisms that cause this type of muteness have not been identified.

Why can we do routine things when we are a bit stuck, but with communication, we have to be supported?

Martha: People with Autism have described how difficult it is to establish skills that require an uninterrupted sequence of actions. However, with much practice, some people can to learn to do some everyday activities smoothly. A problem arises when conditions change, which they often do. For example, a person may be able to set the table at home, clear the table after a meal and wash up the dirty dishes. One might assume then that the person can also do these skills in a new house, or with a new roommate present or when the furniture has been rearranged. However, many people find that even small changes in the environment make it very hard to complete routines that they know very well.

Communication is dynamic and full of surprises. Each time someone says something, it is different from the last time they said it. These continuous changes challenge people who rely on automatic movement sequences to participate. People who speak are often criticized for preferring to converse only on certain topics or for repeating the same questions. I believe that these preferences may be related to the need to create some predictability in the conversation in order to participate.

Donna Williams, an author with Autism, describes her experiences with what she calls exposure anxiety as "about feeling your own existence too close up, too in your face" (*Exposure Anxiety*, 2003, pp.10-11). People who use physical and emotional support to type their communication have similar difficulties. Some folks who started out typing with physical and emotional support, now type without direct physical contact. However, the presence of a 'facilitator' is still an important part of their communication. Jamie Burke, a young man with Autism, has learned to type without physical support and now reads aloud what he has typed. His supporters wrote an article about his journey toward independence The progress and challenges of others can be an inspiration to us all.

What happens to people who are more independent communicators, when they are stuck, or don't they get stuck?

Thomas McKean is a person with Autism who speaks. In his book, *Soon Will Come the Light* (1994) he has described his experience with getting stuck:

> *There are, on occasion, still times when I want to talk, but I can't. I can try and try and try, but I can't talk. There is a fear holding me back. I do not know what it is I am afraid of, I only know that it is a feeling of fear unlike any other feeling of fear I have ever known. It is not that I do not want to talk, it is that I am <u>unable</u> to at that moment (p.39).*

4 Let's Talk About Our Senses...

In several gatherings in 2009-10, we explored our senses, including our perceptions that are affected by the symptoms of Autism. We who have Autism can have stronger reactions to sensory stimuli than people who are "normal" or "neurotypical." We tried out and discussed how we experience our basic senses of smell, taste, vision, hearing and touch. We found that we can differ quite a lot in our likes and dislikes of specific things we taste or smell. We tend to be most hypersensitive to sound and touch.

The Beach by John MD

The beach was calm and serene
early in the morning.
The water was moving very very little
towards the seashore.
The sand was as fine as grains of salt
under my bare feet.
The air smelled of seashells
and sand.
The sky was a clear soothing blue.
A feeling of peace permeated the air

Some of us may experience a blending of senses or synaesthesia. Seeing something may also bring a strong sensation of odour or taste. Or when we hear a sound or word or name, we may see a particular colour. This may be more common among people with symptoms of Autism. It may explain why some of us are artists or express ourselves in poetic metaphors.

Perhaps the interaction of our senses explains why some of us have problems with two other senses-- the vestibular (balance) and the proprioceptive (sense of our body in relation to surrounding objects, people and spaces).

Our families and friends have long known that our sensory systems tend to be hypersensitive, even hyper-reactive, to various sensory stimuli. What was unexpected was finding that most of us see other people in coloured auras corresponding to some qualities we see in them. A few of us who don't see people in coloured auras are very sensitive to other people's moods. Some of us see abstract ideas as colours too.

These thoughts about senses just emerged from the discussions at our Bridges gatherings. The most surprising discovery is about the special colour sense that most of us have. Until this topic came up accidentally, we hadn't realized that our normal or neurotypical friends do not see people with coloured auras. We thought everyone did and are sorry that you miss this!

Perhaps some of our senses are over-developed and hypersensitive because other parts of our sensory and nervous systems are not so well developed. Perhaps too, because we have not been formally educated, as people did not think we were intelligent enough. Our sensing instincts may still be more alive, as they were in earlier times of human development, or as they may be in very young children.

As the members of our group cannot speak with our voices, and may have different ways of perceiving what we see and hear, we may be compensating with some special senses. As well as being hypersensitive, we may have special abilities with music, numbers, memory, shapes, visual arts and words. As people with Autism are thought to find face recognition hard, perhaps it is good that we can sense personal qualities through our recognition of the coloured auras we see around people.

Some of these ideas are explored by the noted autistic writer, Donna Williams in *Autism and Sensing—the Unlost Instinct*. From her own

experience, she suggests that the senses of a person with Autism are "stuck" at an early development stage that everyone goes through. In her view, most neurotypical people move on to a system of interpretation which enables them to make sense of and cope with the world, while they lose various abilities which people with Autism retain. She goes so far as to suggest that "the constraints of space and time do not exist in the same way for autistic people, and that the emotional as well as the physical world is seen."

In this section, we report some of what we have shared about our basic senses as well as some of our thoughts about the less common ones.

What are our favourite smells, tastes, sights and sounds? What are our least favourites, and how do we cope with them?

Smell:

KM: I like the smell of food. It makes me think about eating. I enjoy eating at David's farm because the food smells good and tastes delicious.

KR: I like to smell good things. Lollipops are delicious. Popsicles smell good.

MM: I don't like any perfume but do like the smell of food.

JC: I like the smell of pizza.

AB: I like the smell of ginger and Beth's vanilla scent. I like the smell of the rain in the air. I like walking in the rain.

Taste:

AB: I like peppermint and chocolate but don't like avocado.

KM: I like the taste of Mom's carrot cake because I can only eat it on my birthday. I don't like the taste of food that is bitter, like coffee and cabbage.

KR: The taste of beer and peanuts is my favourite. I like that because it lasts a long time and it stays with me.

SL: I like food, especially banana.

Sounds:

KM: I like the sound of fiddle music. It makes me feel happy and I enjoy listening to happy music. It is good to feel happy in my heart. I don't like loud noises and I don't like shouting. I don't like the highway and all the cars driving fast and passing us. I don't like city buildings. They are too big and crowded. I think I like the peace of the countryside best. I like the cats at the farm. They are happy to see me and they are hoping I will give them food to eat.

KR: I like the sound of the lake. The waves are relaxing. I remember that from going there a lot when I was a kid. I don't like the trucks. They are loud and scare me when they honk the horns.

MM: I like the sound of water and sea water.

JC: I bang my head in storms.

AB: I used not to like the sound of dogs barking but I am desensitized to it now. I like the sound of soothing music and my mother's voice. There is no silence. I don't like the furnace. I don't like loud banging. But I don't mind actual thunder.

Sight:

KM: I like red like my Mom because it is bright and cheerful to wear. I feel I am alive and happy in the red colour.

KR: I like to go to the movies to see scary movies on a big screen but I don't like to sit too close. I also like flowers on the trail walks I go on. All the wild flowers are nice. I don't like everything green. I need colour.

SL: I like to see my family as I love them. I find blood scary.

JC: My face lights up when my mother comes on Sunday to take me home. I like to watch sporting events while rocking in my chair.

AB: I do find it hard in bright light; it bombards my brain. I like green, in trees and T-shirts. I don't like red or orange. Red makes me feel mad—it just bugs me. Yellow is OK.

We passed around a tray of objects chosen by Heidi and Andrew, and typed about how we reacted to their tactile qualities. We mentioned other touch sensations that we like or dislike.

KR: I don't like cold water; it is frightening. I like warm water in the shower or tub. I don't like pool water; it is scary. I don't like the smell of the chlorine or the cold water. I like smooth things that are heavy. I like it when people facilitate with me but I don't like my hand or arms touched. I like soft hands, so people need to have soft hands, but also enough pressure. With touch, the heavier the better. Anything ticklish makes me run away. A hug is hard, it feels like being strangled. I prefer a handshake.

KM: I don't like being touched by the hand if the hand is cold. I like warm hands to touch me like Mom's hand and Beth when I talk with her. They

have warm hands and I like that touch. I don't like being held tight. It feels like I can't get away and be free.

AB: I want to mention that tickling is torture. When people tickle me I will clap because I am upset. I don't like gentle stroking. I like a firm touch. Maybe I will show people how to touch me. [AB brought his brush for E to show everyone the Wilbarger protocol of firm brush strokes of arms, hands, legs, feet, back and shoulders, followed by joint compression]. I relate to Temple Grandin's aversion to touch that is light. I like it that I can teach you new things.

KM: I don't think I would like brushing because I don't like the bristles in the brush. [When tried the actual brush pressure] I don't feel the bristles but I do feel the pressure.

We are hypersensitive to touch—this is very important in knowing how to support us

KR: That is what I feel about touch: the heavier the better. I don't like the idea of the brush, it looks ticklish and that would make me crazy. Don't bring it close to me, please, unless you want me to run away.

MM: I don't like touch when I am not expecting it.

JMD: Touch bothers me most. My hearing aid hurts.

SL: I do not like to be tickled.

JC: I like massage therapy.

KV: I cannot stand bristly things whether scratchy or soft. I hated almost everything in my sensory bag, even the squishy ball with the tentacles.

AB: We also may have acute sensitivities to other things in our environments—such as air temperature, pressure and humidity. Some of us like it best when the air is warm and dry and we are hypersensitive to hot and humid weather. Some of us are allergic to things we may eat or breathe or touch—we have to avoid them or perhaps take medication.

How are we aware of other people? Why do we feel everything so intensely? What works well for us when our senses interfere?

JMD: When John gets upset, hearing fails. Hearing aid helps. Helps to have people understand. I like to carry (elastic) bands.

MM: When I am tired my senses are loud.

KM: I feel intense because I am tired. I am frustrated. Sometimes I feel that I pick up D--'s mood.

KV: My awareness of everything is excruciatingly present at all times. It would be great if there were a turnoff button. I even feel vibrations in the air and changes in the weather. I pick up other people's moods and sometimes feel quite crazy. I get anxious over things that seem trivial to others. Today I am quivery and trembly. I tune things out as best I can, but nothing is ever single-focused. Dark glasses help and standing up and going to another room. It helps to break things down in steps. I need lots of down time. Rides and traveling keep me sane.

I focus best on one sense at a time. I listen to TV and only glance at the visual unless there are no words such as in an episode of scenery. When I am anxious, all my senses are too acute.

AB: I have to work all the time to keep my senses and movements in balance. When I feel unwell my senses are very disturbed—all of them including balance and co-ordination of my movements. My brain and body are in turmoil. I cannot hear and it is very hard to type, though I can be persuaded when people are patient. It is worse when our weather is hot and humid as it is this July. I miss our long walks. Though I have cool quiet spaces in my home, I can feel cooped up. Now I feel nervous and on edge because I have to go to the bottom of the well for my energy. I feel sort of lonely like I am the only one who can lift me up from the bottom. I just need to work through this time of strife in my mind.

It's hard to listen to my body as too many things going on. A large amount of stress on my mind. I feel the need to run fast and furious, but running can make me tireder and more hyped up. With this weather and the way I feel, gentle exercise walking with my dogs is maybe better. At times I feel the need to dash outside to run around my garden— I need to move and see the green. It is a reminder of how much I am part of the big picture in this world God gave us. My routines are important.

We also use the word "sense" more widely in various important ways. What are some examples?

Sense of humour. Sense of danger. Sense of security. Sense of God or spirituality. Commonsense. Sense of time as in routines. Sense of place or order. What about ESP (extra-sensory perception)?

KM: I have a sense of God when I am in the barn. It is quiet and I feel relaxed there. I think I hear peace. I like the farm work because I can be quiet and listen to the sounds in the barn.

KV: I need to feel secure. This includes the confidence of being with people who understand and respect me.

SL: I have a sense of humour and like to share it. It's good to laugh. A sense of security is important; my family gives me that. A sense of danger: God keeps me safe. Order and routine can be important—it's sad when I don't know what to expect. ESP is picking up people's thoughts.

KV: Autistics have ESP to a higher degree than other people. This gives us a uniqueness that is special and valuable. We have awareness of the feelings and moods of people and animals and plants. There are times when we feel the presence of God and family members who have died. I am also visited by my guardian angel. St Clare is my special saint who is often with me.

KR: I think I have ESP with people. I am in touch with people and how they speak to me is a way I sense what they are feeling. I like to watch people and can get a feeling of what they are feeling. People don't have to say anything to say a lot. It's a lot of ways to talk: people forget I can hear well. I sense their fear in me. I am a lot of feelings bottled up and when I get to say things I cannot stop. I think people don't take the time to talk, really talk. They don't take time to communicate.

We may have synaesthesia, two or more of our senses mingling...

KV: When I hear sounds I think of pictures and colours. Everything I think of is in pictures. The pictures are in colours and symbols. Other people would only sometimes understand my pictures. The pictures are in vivid

colours—red, purple, green, black, blue, yellow, white, orange—but often lots of red and purple swirling around like a huge tornado.

We have begun to exchange our experiences of seeing people and ideas in coloured auras. I previously thought everyone saw auras, but have discovered it may be a special ability of some people with neurological and movement differences like Autism.

We got into this discussion by accident. In June 2010, when I greeted Beth who had just arrived to visit me: "I think you are in an anxious state. I get a sense by your aura. I mean I see the aura. It is waves of colour around a person. I see yours often. You give me a sense of deep caring but today it is different. I usually see a pale sea green... like the ocean. I see you in your sea greenness and you show me you are open to me. You are loving, and it makes me feel accepted and calm. If I am with a man who is closed he is grey brown putty and makes me want to shut the door to my mind. I see many shades around me. I thought everyone did. It is too bad for you if you cannot see it. It is something I have and maybe makes up for some things I don't."

I decided to ask my Bridges friends if they see coloured auras around people. My other friends were really interested, and Lea, Heidi and Deb helped me to understand more. I learned that perhaps we are able to pick up on the electromagnetic field projected by another person's chakra or major energy centres. The chakra idea includes colours, personality traits, food preferences, musical notes and more. We tried out the chakra chimes that match the various spectrum colours. Then we put the following questions to other Bridges members, and discovered that most of us have this special sense.

Do you see something like an aura or a colour/shade when you are in the presence of others? Or even just thinking about people you know? What about people you haven't met? Do you have a sense of bad or evil people?

JMD: John is purple, Mom is purple, Dad is orange. I am also good at seeing people's natures and moods. I feel really happy when I see a pretty girl.

KV: Yes I see auras with people. It's like a coloured haze. Usually I see purples around mom and reds around dad. J-- is pale blue like J--. All the colours are wispy and pale. Bad people are grey and thicker—less wispy. I don't see any auras around dogs. C--'s aura is purple—darker than yours which has tints of red. R-- is rusty red, not really brown. It's wispy and comforting. As far as I can tell, I have a green aura. Andrew and John and Ken are also green which is an especially sensitive nature like a wild forest creature. We need to be protected from lights and noise. Why doesn't everyone see auras? I think they don't know how to use their brains. Red is my favourite colour, but it has nothing to do with auras.

KM: Dad is blue, Mom is red, Donna is yellow, Vera is red and I am red.

MM: Mom is purple.

KR: I see people who are nice to me in colours red and green. K-- is blue. J-- is red. I am red. [People who are not nice?]: I see them as grey or brown. I want to say that X—is black. He was not nice to me. I don't like him at all. He is a jerk.

TM: [by email from Antigonish] I see my mom with a purple aura and my dad with a red aura. My two main supporters have deep blue auras. The director of the L'Arche community, is red, but with blue as well!

Red is the colour around people who have difficulty talking about what they feel or about themselves, though they are passionate and good. They are not always calm.
Purple auras are around people who are "very hard on themselves".
Green people are in a hard place that they are struggling to get out of, but they are good and are doing their best.
Blue is a wonderful colour: people I see as blue are good to themselves and to others, and they are calm.

SL: I feel a lot like that. I don't see a colour, but I feel others' feelings. Maybe I feel too much sometimes. I get happy around happy people. That is better than sad or mad people. I like to be happy. I like to be here. You give me that feeling. There are no bad people. They just have bad choices and they then become bad in others' eyes. Everyone is a good person, but we don't always have to like them.

AB: The shade or density of a colour can change often, from being light and wispy to more solid and dense. It isn't about knowing people well–I usually do see something. Just thought that was normal [What about bad or even evil people?] I would think that there are muddier colours when the evil comes out and chakras are blocked. I have gotten bad vibrations and those people tend to be colours I can't describe. I also see auras around other things as well as people. My dogs I feel are blue, and Yukon has more red tinge. I also think in colour around ideas, feelings and memories. Hope is blue. Caring is blue-green. Intellect is red fire. Patience is blue. As to negative thoughts and ideas, panic is dark brown and black, and fear is grey.

The discovery that most of us in the Bridges group see people with coloured auras raises all sorts of questions in the minds of our friends. It's important to remember that seeing other people with coloured auras

is our perception of them in relation to ourselves. It does not mean that they are exactly that way or appear so to others. This way that we see others is very interesting. It might be useful in interviewing support people, or in knowing whom to trust when we need help.

How Our Senses Affect Us and Can Help Us

Two Bridges gatherings in 2009 focused on exploring how music and rhythm affect our sense of well-being and the idea of using our hearts to calm our minds in nature.

Sound and Rhythm in relation to our Sense of Well-being

Deborah Seabrook, a Bridges friend who is a Music Therapist and on the faculty of Wilfrid Laurier University, has met with us to explore our responses to sound, rhythm and music, in relation to our total sense of security and well-being. When I asked her what part of our brain responds to music, Deb explained that music makes us feel more engaged because it involves both hemispheres of the brain, as opposed to language which uses just the left hemisphere.

In our first music workshop, Deb played four different pieces of music, with time for us to comment on how each piece made us feel. She suggested we might close our eyes, and take deep breaths to help us concentrate.

"How do I hear and feel sounds, rhythm and music--in my heart and emotions?" we were asked, when hearing a Bach piece.

KM: I like that kind of music. I felt at peace and I enjoyed listening. I think we should listen to more music.

SL: It makes my heart feel warm. Like a Merry Christmas sensation.

KR: The music made me feel nice inside. It takes over my sense of sight. It is an awesome thing that takes me to a happy place.

AB: I hear the music in my head and then it makes me feel like swaying. That means pleasure.

JMD: [who can only hear piano music, because of his hearing loss] I hear the music and feel good.

KV: I felt that music in my soul and whole self. It was beautiful and lovely and tranquil. It reminds me of my childhood and my mother's studio.

MM: Nice to listen while I think. Emotion is wholes and cares big and small.

With a second piece, we considered: ***"What do I feel listening to different kinds of music?"***

KM: I feel happy like I want to dance. I like the happy high notes. I can see myself jumping and clapping to the music.

SL: It made me feel like dancing. I can't sit still when the beat gets fast. It makes me want to move.

KR: Felt better than the last piece.

AB: I felt uplifted and my blood pressure went down. I know that because I feel myself doing it. My feeling is we should use Deb instead of drugs.

JMD: Good music, happy, feel joy.

KV: That music was too loud and discordant, but it had a lively rhythm. I wanted to keep time with my body. I also wanted to cover my ears.

AB: I also want to cover my ears when music is loud.

KR: It depends on what you like. I prefer a loud thumping noise but the soft sounds relax me. Maybe you want to be relaxed now, rather than revived. It is good either way. We are all different. It makes us unique, just like the music.

Listening to the third piece that had no consistent rhythm, we thought about the question ***"How do sounds, rhythm and music affect our ability to express ourselves?"***

KM: I did not like that music. I felt I wanted to block my ears. I don't like slow music and I don't like the odd sounds she made on the piano.

SL: I felt like something was needed to complete it. Waiting made me feel a bit worried. I like being able to expect the song. It is calm, but too much of wait.

KR: Nice but too slow. I feel tired. I think we are all so different and that is very interesting. We are all so unique.

AB: I really related to that. I like piano. Electric guitars or drums bother me. This one would be good to go to sleep with. Very mellow. Quiet flowing music helps unlock my thoughts.

JMD: Sad music helps me to think about grandma.

KV: I liked that music. It was like a relaxing walk along a nature trail with frequent pauses to read the signs or listen to the sounds.

MM: Like that one, very slowly. Music is nice in all shapes and sizes.

SL: I liked to listen to the music. Neat to hear how different everyone's opinion is of it. Kind of funny I think.

Deb then played a new piece she had composed and asked how it affected us.

JMD: Happy music makes me feel good.

KV: That was interesting and sometimes unsettling. It was descriptive, sort of like a long conversation with lots of commentary and questioning.

MM: I was trying to right myself [and the music helped].

KM: I liked that music. It is happy and dancing music. I liked the notes skipping fast in the music. I think I like listening to happy and fast music, not slow and quiet music.

SL: That was beautiful, and makes me have that Christmas feeling again. It is an event waiting to happen and when it does, it is a welcoming feeling like being here with my new friends. It is a good and peaceful thing. I like it.

KR: Good but slow. I think this one was very beautiful. It trickled like running water. It is a feeling of water and trickling brooks and like the waves at the beach when I was at Mom and Dad's at the lake. It is a lovely feeling of contentedness, if that makes sense to you. I can't explain how nice it is. Just water is a good thing.

KV: I agree that it sometimes sounded like rippling streams and bubbling fountains.

AB: This one would be good to have as background for my typing.

Using Our Hearts and Senses to Calm Our Minds

Lea Tran, our friend who is Horticultural Therapist in The Guelph Enabling Garden, led our thoughts about how being in natural environments and working with plants can quiet our minds and give us a sense of peace and well-being. Being in such a garden and appreciating its beauty can make us feel calm and relaxed. We asked ourselves: What is it exactly about nature that makes us feel so peaceful? What changes must occur in us so that we are able to interact with nature to benefit from and to fully appreciate what it has to offer?

Lea explained the idea that "feeling united with nature creates a sense of well-being that can best be perceived through our multisensory bodies rather than through the predominant linear thinking patterns of our minds."

She invited everyone to say what we enjoy about being outside in nature, going for a walk, or being in a farm or garden. We agreed that being outdoors can give rise to more positive feelings because we can interact with all our senses of smell, sight, sound and touch. (The only problem for some of us is our allergic reaction to some plant materials).

JMD: Going for a walk in a park makes me happy. I love God too when outside.

KR: It is a good feeling to be outside. It is like I am free from noise and smells. Even though the outdoor smells annoy me too, they are natural, not cleaner, smells. I like to see things that make me feel good, to be part of this world. That might sound corny, but it is a really weird but good

feeling. It is really calm and quiet when birds talk. Boats in water--that is a great sound.

SL: I like walking outdoors and to see things. I feel close to God and nature. I feel good and whole.

KM: I feel great outside because I am free to move around. I like the smell of the horses because they are big and I can touch them. The barn smells of animals and I like that smell. I like being outside in the fresh air. It is fresh and clean. I like the freedom outside because there is lots of space to move around. I have a sense of God when I am in the barn. It is quiet and I feel relaxed there. I think I hear peace. I can be quiet and listen to the sounds in the barn.

MM: I enjoy the lake.

KV: I love the peace and freshness of nature. I feel alive and, at the same time, relaxed.

We went out into the Courtyard Garden at the Ignatius Jesuit Centre of Ecology. Lea showed us how we could communicate with plants, and they with us, through energy waves, including heartbeats. Our newest member Sara, after walking around the Courtyard for the first time, chose the "tall, pink flowers" (Echinacea or coneflower) as the plant on which we would focus, by standing close and sensing its qualities.

We thought about these questions: ***What emotions do we feel in the garden, and where do we feel them? What do we feel? What do we see? What do we smell? What do we feel (touching)? What do we feel (emotions)? Then we focused on our hearts, and breathing in the plant's calming energy.*** Some of our comments are captured here.

JMD: I feel good, in my brain. I see trees, flowers and people.

AB: I sense the beauty through my eyes and feel the colour in my heart. I feel the wind energy. The cone is prickly and rough to touch.

KM: I feel OK because the plant is pink. I feel fine and I like looking at the flowers. I can see the plant. I hear the wind. I use my eyes to see. I see the plant moving in the wind. I use my fingers to touch the plant. The leaf feels rough. The centre feels rough like the leaves. I am happy to see the flower. I just look at the flowers and see colour and shape. I don't feel energy from the plant. I just think it looks pretty and I enjoy looking at it. I think it makes the garden look nice and I like the peace in the garden. The plant invites me to enjoy looking at it.

KV: I feel joy because the plant has such beautiful flowers, and I feel it in my stomach. I like the sound of the wind whistling through the trees. I see the beautiful rosy petals and the green leaves and the graceful stems. With my skin, I feel the leaves are rough and raspy and the centre cone is like a burr. I feel the energy of the plants as a force of greens and blues, and I feel this in my centre near my stomach. The [pink] colour of the petals is different from the energy forces. I love being here in the garden and it loves people looking at it and staying with it. I feel that the plants and I are friends and that we feel the presence of God in our midst.

KR: I don't always feel at peace outdoors, but this is a better feeling. I try to run to get my feelings out but I get stopped so then I feel bad so I just feel sad. Then how do I get out my feelings? I run inside or just wait until I can go outside. Then I can't be at peace in my home. Why not?

Later when back indoors in the meeting room, KV shared more: "Autistics have ESP to a higher degree than other people. This gives us a

uniqueness that is special and valuable. We have awareness of the feelings and moods of people and animals and plants....Plants have awareness of thirst and cutting. They emit sounds and colours like an aura. All of creation throbs with smells and colours and sounds. Even stones have sensory emissions but theirs are muted."

Lea noted that there can be good physiological changes in the body when we are sensing with the heart. She explained how important it is to use senses and heart emotions, rather than just our rational thoughts when relating to plants and nature. She said that we can train our senses to recall a good past experience of meditating and communicating with nature, and also to meditate again by ourselves now we know how. We tried this together at a later gathering, when visiting The Guelph Enabling Garden, and some of us also did it on our own at home.

I tried communicating with a plant in my home garden. It was the black pod shoo fly. I chose it because of its unusual colour and shape and as a metaphor: beautiful but toxic. I chose it being unique myself too. What did the plant say to my emotions and heart? Delight is best word. It speaks to my visual and intellectual senses. How did I find meditating and communicating with a plant calmed my brain and hyper-reactive senses? It is the whole garden, not one plant, that does that. I do feel it.

5 Sharing Struggles and Strategies to Improve Our Lives

We live with complex challenges caused by the movement and sensory differences in our brains and bodies. These may be very painful and are always there, even when we seem calm. Some of us also have particular disorders in our nervous and sensory systems. We may have epileptic seizures, obsessions, addictions or other health-related difficulties for which there seems no solution or cure.

What can hurt even more are the ways other people may not listen to us or understand our difficulties, abilities and dreams. Facing change or transitions is hard for us anyway, and harder if nobody takes the time to explain what is going on or to ask for our thoughts and choices. We can feel very lonely and frustrated by these barriers in the way of relating to other people or living fairly ordinary lives.

Of course we try to balance the struggles by typing about positive and hopeful topics. We all have a sense of humour and express empathy with others, which may surprise people who have stereotype views of Autism. Even when I disagree with someone, I try to say all the good things I can before adding "but...."

Each of our gatherings includes times to share our struggles and to think together of strategies that could help. But they include the frustrations of not being understood or listened to. We have already outlined what it's like to live with our movement and sensory differences (Chapter 3).

We have a lot in common. My friends know my language. We are calmer here and support each other. We have a place to talk things through and work out the ideas together. We listen to the struggles we share, we root for each other.

It is the knowing that our bodies are not in our control that makes us like a family--related. I think the struggles are in our bodies, and the strategies are what help.

Our struggles are often too personal or intimate to quote by name, but here are some special concerns we struggle with and have shared with the Bridges group:

- I want to know how to deal with feeling alone--when people don't include me.
- It is hard to be deaf as well, so hard. I feel alone and sad.
- I feel deserted by my friends.
- I feel that way a lot too. I don't know if I will ever feel totally included unless everyone communicates with me in some way. Like people talking when I am not in the room; I can still hear them and that makes me angry and then I feel alone, like no one is listening to me. Just remind people to talk to you and then put an effort into talking. However you can try and try; I have to. Even when I hear, I feel alone.
- Addiction is like a demon in my head.
- My obsessions are still strong.
- Having Autism is always being run by your brain not always working, but what I eat makes a difference.

- My health is always on my mind. Health and mind are like cause and effect. I do not know where one begins and one ends, but it is like sunshine to my brain cells when it is all working in harmony.
- When I feel unwell, my senses are very disturbed. I need support to cope with my feelings. But how do we make our needs known when we can't identify them ourselves with so many things going on? I just need to work through this time of strife in my mind.
- When I am in a bad mood, I feel tired and sick and worried about everything. Sometimes I can stop if the occasion calls for making a good impression, such as planning for my future... At meetings I can do it, and collapse later.
- When I feel myself slipping into ill-health and bad moods, I don't know what to do. It helps if my family or companions are good to me and don't get mad at me.
- I feel on edge because I have to go to the bottom of the well for my energy. It feels sort of lonely like I am the only one who can lift me up from the bottom. I often feel this way.
- I am rarely allowed to follow my impulses. It can be tiresome always having others remind you to do or not do things. I think it is like a dog likes to stick his head out the car window sometimes and feel free.
- It's hard when things around me change unexpectedly. I feel agitated in my body and confused. To help me cope, tell me in advance. It helps to tell me what I need to do and reassure me I am supported. Less words, some gestures. It doesn't help for a support person to repeat words, yell or get agitated.
- I get dizzy when I look at things straight. Looking straight at keyboards is hard, because of confusion in my perceptions.

Supported Typing together in our Bridges-Over-Barriers gatherings is a precious chance to share the struggles of our everyday lives with others who understand. Though our lives and circumstances are different in detail, we understand one another sometimes better than anyone else does. Some of us may have already got through or over a barrier that is impeding one of us. One person's strategies may not help everyone, but there's a good chance that something one person has made to work may help someone else.

An example is the value of a social story when we are facing changes of some kind—such as in transitions to new experiences, environments or support people. A social story allows us to read, or listen to, type or compose in advance, and rehearse what to expect in social situations. Four kinds of sentences are used in a social story: descriptive, telling what people usually do in particular social situations; directive, giving positive guidance to the individual as to how to act in specific situations; perspective, presenting others' reactions to a situation (something a person with Autism may finds hard to imagine); control, with strategies the person can use to help remember and understand the whole social story. Social stories can help us to become more independent in routines, and know how to do an activity, how to ask for help, and how to respond appropriately to feelings of anger and frustration.

Selecting from all our discussions, we have chosen to feature these topics in the rest of this chapter: our sense of security and the vital role of family and friends as safeguards of our good lives, and how we can help one another to prepare for future changes in planning our own lives and making our own choices.

What makes my life worthwhile?

JMD: My great family, friends and support staff help me. Swimming, travelling, Bridges friends.

KV: My family, brothers, Bridges, communicating, art, advocating for others.

KM: I am happy at the farm--I like people to know that about me. I am not happy in the city. People are too stressed there, and they can't accept my disability well. I like my Bridges friends very much: we need to support each other. I want to be happy and kind all the time. I like walking and car rides.

AB: Walking my dogs, gardening, cooking, typing with support and on my own, and typing at gatherings. I don't want to pretend I am independent, but I am in many things.

TM: I work to be calm. Things I am doing now—going to the park and to library. Going places with my parents. I like coming to Bridges and being in a good frame of mind and talking with you.

MM: Friends are what make me happy. When I am happy with the world like I feel today.

What does security mean? What do I need to feel a sense of security?

JMD: I need a great family and good friends. Understanding what is going to happen and really being Dad's partner.

KR: Having the people I need in my life, not the things. It's nice to have things, but people are the best thing to feel part of a secure life. I feel most secure with my mom... I like to be with people who know me best, not with strangers. They fear me so I feel a bit insecure. Probably like they do. I like the feeling of a safe home, like I have ...

SL: I feel secure when my parents are with me. It is feeling safe and at home with people, not with strangers. I think secure might mean money to some people. I think that sometimes gets away from the real meaning and people get lost... I need money, but people are more important to me and I know my parents will make me secure if I have them in my life.

KM: I need people who need and love me and believe I can do things. I feel secure when people accept me the way I am. I need people to think I am smart and I can do things. I am secure at the farm because D-- likes me and likes having me at the farm with him. I feel secure at the farm because I can do the work and I am a good worker.

AB: It means being safe with no worries. It means being sure I am OK and not left in uncertainty. I need to be with the people I love and who know me. I think knowing me includes knowing what I need such as good diet, S-T, time to get going, and my dogs.

What the qualities of families that make us feel secure?

KM: My family gives me security by being with me all the time. My family tried to help me do interesting things and they have meetings with people who help me have a good life.

SL: I love my family. They have always been supportive of me, almost too much because I have always had them.

KR: I love Mom so much. She always loves me even if I am a jerk. ... The feeling that Mom gives me makes me know that I am good and respected by her. It is a good feeling. ...The thing about family is that they love you. No matter what, they always love you.

JMD: Kind people help me to have a good life.

KV: Family accepts you unconditionally. They love you when your behaviour is odd and they have faith in your capabilities and intelligence.

AB: My parents know me, listen to me, and work with me to make my life fit me.

How can we have more of the qualities of families so we feel secure and more independent?

KM: I need help to go out in the community because I can't speak words. I need people to S-T with me and be my friend. I need more people to understand me and take me out to work at the farm every day. You have to have patience with me all the time.

SL: I can let people into my life so they get to know me. If I put it out there then maybe they'll enter my world.

KR: Just how do I tell ... how to love me, how I need to be loved? It is so hard, dealing with all this. This brings up so many things and feelings for me. [It] almost hurts, but feels good to share too.

JMD: Treat me like a man—everyone!

AB: I think welcoming others to Bridges and our ideas will help me get known and feel more secure. I want to practice typing with less support. I have enough independence for me in my home, like jobs and dogs.

KV: We need to be able to communicate with others spontaneously. We need to entertain ourselves and, as far as I can tell, look after some of our own care.

MM: You will tell them to respect me. Try to feel my Autism. Respect everyday. Happy to have my family cheer and teach.

KV: Other people need to accept me better. I need to find ways of interacting with them. Then they will respond accordingly.

JMD: Help me to make friends.

AB: I need others to learn from G and E. I cannot depend on them alone. I need to tell people what I need. By typing and inviting others to listen. I need others to learn from me by spending time with me and at Bridges.

KR: I need to trust other people to be helpers like my parents, but I need to know people well to let them in. Our lives are not in our control, so I need a plan.

SL: Feeling loved by family is because they know me. If people get close to me, they will know me and love me too. That helps me to be a better person in whole which will help me improve my life. I want all people to love me. Just get to know me.

AB: My Aroha friends are very important, now and even more in the future. They know me well and have the legal powers to help me make the key decisions. They are core members of my circle of friends who have legal powers to help me make choices and direct my own life.

Who are our friends? What qualities do I want in a friend?

TM: Our friends are the people who can be with us and not get upset--the people here, my circle members and my family.

RA: Friends are people interested in us--my family, the ACES group and here.

KM: My friends are the people here at Bridges. They accept the way I am. I like calm focused friends who listen to me speak.

JD: People who want to get together with me

KV: My family, Bridges friends and housemates. People who are caring, interested in my thoughts and believe in me.

JMD: My friends take time to know me.. My family and people here.

AB: My friends care enough to take my particular interests in their minds.

Why do we need friends?

AB: Nobody can be alone in the world. I have things to give as well as receive.

TM: We need friends to stay alive and be who we are and not what people think we are.

RA: We need friends for company and to share ideas. Life without friends would be so lonely.

MM: To eat and live well.

KM: I need friends to like me and to do things with me. I like being with friends who like being busy, like working at the farm. I like friends who like to go for walks with me.

JMD: We need friends to get to know us, good people.

KV: In order to have companions and people to share experiences and happy and sad times and to explore ideas.

Do we need different kinds of friends?

AB: Yes, we need to share interests like other people do.

TM: I think we do [need different kinds], but I cannot think about it now because I am thinking about our move to Nova Scotia and whether I will make new friends there.

MM: Yes, they have different gifts and we go places.

RA: Yes, we need friends our age.

KM: I need friends who like being outside because I like going for walks. I need friends who like animals. And I want to be with friends who like to eat healthy like me.

JMD: I need friends to help with S-T, go swimming and out to eat.

KV: Of course, because the world has all kinds of people and that's what makes life interesting and worthwhile.

How have I made friends in the past?

KV: They have been in my life already or others have introduced them to me. Some have introduced themselves.

JMD: I made friends at school, at PH [my day program], here, at home.

KM: I did not make friends in the past because I did not know how to and I did not speak by S-T with anyone.

RA: I made some friends at school and working at ARC, also at Andrew's house where I used to go on Thursdays.

MM: Working is great.

TM: I make friends by being with people and trying not to get mad and being in a good mood.

AB: I think we have to share with others. I have made friends by inviting people to be in my life and to come for dinner and see my garden. I think most families are too nervous to go after new people.

Where might I look for new friends?

TM: I think [when we move to Nova Scotia] we might find them at L'Arche and at church and in our new neighbourhood.

RA: We can make more friends at work and by inviting people home.

KM: I make new friends with my sister. We go to church together on Sunday and our friend introduces us to new people there. We could talk to people we meet in the stores and our neighbours next door.

JMD: New friends can be hard to find.

KV: Shake hands with friends and people who visit us and when we meet them, so they can't ignore us.

AB: I think the paper is a bad place [to advertise] for friends and workers. We need to go places, talk to people, try new things, and ask our friends to introduce us to others at church and parties.

How do you tell people you want to be friends?

TM: I show them that I want to be friends by smiling and shaking hands and being in a good mood.

KM: I tell them I want a friendship with them by looking at them and sitting down beside them. Smile at people and shake hands with them

JMD: Try to smile friendly.

AB: Showing up with my dogs always gets people talking. I think smiling helps too if you can get your mouth to do it. But it is hard when people touch me if I don't expect it or don't know them.

KV: Tap them on their arm. Bring them your portable small PC. Don't make angry faces. Look pleasant.

How do I tell a friend that something she or he does irritates me? Should I just accept it?

KV: I look into their eyes and stare at them, hoping they understand. I try not to lose control because then they don't know for sure.

JMD: [of specific person] I would get really mad and push her away.

KM: I can tell them I am angry by shouting them or leaving the room. I can sign No in front of them.

RA: I just let them know I don't accept it.

MM: It is hard.

TM: I think I should tell them, because if I do not I will get mad and they will not be my friend any more.

AB: I get E to tell them in polite words how I feel. It is hard to ignore some things but maybe we should try to be patient too.

Top ten suggestions for making new friends

KV: Have T-shirts made with a small Bridges-over-Barriers logo and large words saying "Talk to Me!"

[Everyone liked this as the #1 idea and voted for "Talk to Me!" rather than "Talk to Us!"]

KV: Either is OK but "Talk to Me!" would make people respond personally.

AB: "Talk to Me!" is better. It is an invitation, just like when my dogs help people to talk to me.

RA: I like the T-shirt saying "Talk to me!"

[We discussed the design of a bridge for the T-shirt, most of us wanting the design to show people rather than just the structure]

AB: I think our bridge should be of people making a bridge over an imaginary barrier.

MM: We are part of the bridge; it should show that.

KM: The picture of a bridge means connecting with places and people. I think that a bridge is a good picture to put on a T-shirt because it tells people I want to talk to them. I cross over to meet them and we meet half way on the bridge.

Other suggestions?

AB: Do more inviting to others to become friends. Do not be shy about reaching out to others who share your interests. New environmental initiatives to get people who care together. Chat more with people like your neighbours. People who are friends already can find new friends for us.

TM: I think it is a good idea and I hope that we will do that in Antigonish and I will try to be very good. I think that we could go to the place where there are other people with disabilities and be their friend.

JMD: Be friendly. Make good friends by having parties.

RA: When out for a walk, say Hello more. Inviting people is a good idea. Play board games and card games with people. I need help from my parents in inviting friends.

KM: Yes I should invite people to be my friends. I could go to dinner to meet more new people. I would need someone who is already a friend or supporter to help me talk and answer their questions.

KV: Be tolerant: look happy when people get close. Looking pleasant for the sake of other people. People might be pleasantly surprised that we can be sociable.

Directing Our Own Lives: How to Have More Choice and Control

Living with our movement and sensory differences is hard enough. Being assumed to be incapable of thinking and making ourselves understood is another big barrier. People may have thought that all we need is to be cared for in a safe environment and have all our choices made for us.

In the past 20 years people with disabilities have been asserting their rights to understand their options and to make choices that affect their lives. People with physical disabilities led the way in Canada in "changing the way we view disability" through the Independent Living Movement. It is taking longer for people with developmental disabilities, though self-advocates in People First have been speaking up since the mid-1990s for our right to be involved in all decisions that affect us. One mantra is "Nothing About Me Without Me!" Another is "I have the right to choose where and with whom I live and how I spend my time."

Members of our Bridges-Over-Barriers group live in different circumstances, with varying kinds of support—some of us in our family homes, some in group homes maintained by agencies, and some in homes of our own. In our gatherings we often talk about our hopes for the future and our concerns about change. During the past seven years, several of us have begun or carried through transitions towards having more choice and control over our lives. We have learned from each other's experiences.

We welcome the Ontario Government's new law about policies that could support us in our transitions towards more self-directed lives, with the help of direct, individualized funding and independent facilitation and planning. We still have to speak up so that supporters and policy-makers will listen to the way we communicate. And we have to work out our own strategies to adjust to any changes in our environments and activities, however good these changes may be.

In our gatherings we have had several conversations using Supported Typing, about what we most want in our futures and the kinds of support we need to realize our dreams. Here are some examples.

Thoughts about growing and independence

--I was thinking that we are all growing so much now, my Bridges friends, are we not? I have grown in confidence.

--I think growth is about us getting together here, and about the rapport we have developed and the friendships we have built. I hope this keeps growing in the future so we will be enduring. We should have a permanent place like here where people can come and stay for varying lengths of time and where they can learn.

--It is about the things that I do in my mind and heart and I am very much afraid that I am not going to grow as far as I should...

--Growing means not staying still and being ready to learn new things. It means learning to talk well and studying new things. I like studying new things, especially at the farm.

--Changes are hard and difficult, but I need change for growth.

--I think growing is about being in a good place. I think this is a good feeling. I think this is a good place. I think I am more in the world now. I have a diploma and I am in a happy mood.

--Growing means to look forward, plan for good lives, and make choices

--I like to feel independent and respected when people listen to me and don't just not force me to stay on track.

--We are always being told we must become more independent, in communication and our whole lives. We try our best...

--But nobody is absolutely independent. We all need each other.

--We are all interdependent. I do not want to be independent.

--Everybody needs companions and it would be a lonely world if we were left completely alone. I believe that my family and housemates benefit from my friendship and company and humour.

--We need each other because we cannot do everything by ourselves.

--I understand about being interdependent, but I think that we autistics get the message that nobody needs us.

What things do I want people to know, so they can support me well?

--People should know I am smart, though hearing-impaired.

--I'm intelligent. I need encouragement, not bossing. I have a diet which I need to follow. I like to make meals with friends. I like to teach--about our way of being in the world, and how we need support but not

parenting. I hope to get our Bridges centre going. My days must be flexible.

--I would like them to know that I am smart. I can do things. I do not like to be talked down to. I think they should know that I have a good life with my parents. I love them so much. I want to be close to them. I am not an angel and sometimes do stuff that they will not like. They should be patient and not get mad and be my friend anyway.

--Support people need to be flexible and encouraging. So keep trying in many ways: don't give up till you try many ways. When we need flexibility but don't have it, we get agitated. I will say No in many ways. People will know by the way we are in the world.

--I need people to hear me, when I communicate my way.

--I want to get out more.

--I would like to be treated like an adult.

--It is good to be able to talk about things with others before they do things for me. I need Supported Typing for interviews with new support people.

--I need to keep widening my circle of friends.

--Before S-T it was terrible to meet new people who were supposed to support me.

--We can only initiate conversation with S-T.

--I need S-T to live well with others and they need to be able to use it.

--I have used S-T for nearly 20 years and regularly for the past ten years. I guess it has made all the difference. My voice is heard now.

--My life is better because I can talk to people. I can tell people what I want. I can share my dreams. I am happy that I can talk to people. I have a support group to help me follow my dreams.

--I want to have a friend to be with me and go places. But I want chances to be more adult, so the person needs to be able to know when to help and when to say "Go for it!"

--I want to be more independent but I still depend on others to make connections.

--We need to be allowed to make our own choices and to try new things.

How do I fit in the world: Do I feel included? With my neighbours, my family and friends, my city, my country?

--I feel included with everybody, but mostly with family and friends.

--I do fit in the world very well. I need to control my impulses and I need to learn how. It would be better if I could be calmer when I am with people.

--I think being known and being with a good person who is very like my parents.

--I am included at the farm. I can wander and not get into trouble.

--I feel that I fit in my house and community. I am known in the community and have places to go.

--My world is safer and better now, but I'm not sure about the future.

--I love to vote in the election. I carefully listen to the candidates and my family's ideas. Then I decide. I feel it is my duty to show autistic people can be good citizens. I get to do things comfortably because people help me. I become familiar and do more things. My dogs build bridges for me in my neighbourhood: people can better relate to me and respect me.

How well included am I in making life plans?

--Hearing helps me to be included.

--I don't think my life plans could be made differently.

--It should be me with help from others.

--I try to be included in all things about me, which is how my life has been designed. I get to be included in everything because I help plan my life. A circle should help you be sure to be included. It is sad if you are not.

-I enjoy talking with others who share my interests.

--Life planning means our voices. My circle does nothing without my voice.

--It helps me to have a facilitator to help me and explain what is to happen. I come to my circle meetings and I tell them what I want to do. It means that my voice is heard and I make the choices.

--I find it helpful if I am included because I know I am valued. Ask my opinion. Communicate my way. Respect me and listen to me. I need help

to answer, not to understand. What bothers me if that if I use S-T, I am not always believed. I know I need to try harder to be independent. I want to say that it is essential to hear my voice. No decisions are made about me without me. I do it with help from my Aroha. *[Idea of Aroha, the core members of a circle of friends, who know a person well and have powers to support her or his good life and keep it going into the future.]*

--I think an Aroha is a very good idea. I need friends to help me.

--I have a circle too and they are all my good friends and I love them all.

--I would like to have people who stay in my life like that.

--An Aroha is a great idea for providing a reason to bring together people who are important in your life like brothers and some cousins and new friends. They would help me with my plans for the future and be involved with my well-being.

How to cope when familiar friends and support workers leave us?

--You can help me cope by talking about the changes. You have to help me keep going because I get stuck and cannot move. I appreciate people encouraging me to accept the changes. Help me think something positive about the change.

-- It is a hard life. Sadly we must cope. I have had many people leave to go somewhere else. The only way to cope is to keep going and keep routines consistent.

--Keep going. I am just beginning to understand.

--I think we keep going by being ourselves and not getting mad at the world.

--I think firm encouragement and watching my diet help me to keep going.

--I am happy that my Bridges friends are here to encourage me. Thank you for listening to me. I need your help now. I am OK. I will learn to take care of myself. I will learn to type by myself so people will know what I want. I will behave well because I want people to like me. I will be calm and patient so the new people can learn to take care of me.

What is important about individualized funding? How could it help me to build a good life?

--I guess it means decisions are made about what's best for me and not for some group. It means my life is a good fit for me, not for some idea about someone autistic. We can get away from stereotypes.

--It is important to have money to live on. We need money to pay the rent and money to pay the workers to help us in the community. With IF, I will be able to do work I like. I would work at the farm every day instead of going to the city to do boring things.

--Very important. I can be independent and make choices about who we are with and where we live.

--I am in charge of my life and I can be with people I like.

--We need to get used to talking with trusted supporters, not just our parents.

--My closest friends and family with my voice make the decisions. I like it this way. An agency is not needed to make my choices for me. As long as people control the choices about their lives, they can have help looking after the accounts. I want everyone to have IF.

Individualized Funding
for Self-Directed Lives

I like to be a pioneer
but it is too slow and scary sometimes.
I have lots of good people in my life.
My Aroha and GSA will go on
supporting me after my parents die.

I think IF has made
all the difference for me.
I might tell people
that it is essential to get IF,
because it is the only way
to give people choices and options.

We must have the freedom
to have our own life,
choose our own path,
choose our own supports.
I think we need to know
we can provide
for our own supporters,
so we can choose good ones.

How does communication figure in my sense of security?

--I don't have enough communication. I get insecure when I can't communicate with people. I don't like to be forced to talk if I am not ready. I get scared if I try too hard but sometimes it is too much like talking. I want to S-T more but I am lazy and don't do it enough.

--Directly. It is really important. I think this group helps me feel secure to talk with others who feel the same way. I feel secure most when I can talk about things I want. To feel security more and more maybe this will be a step.

--Having [my communication device] helps me feel secure. It helps very much.

--It is big big big. The ways I communicate are numerous, by S-T, by sign, by moving. If people are not tuned in to my communication, I am not secure. I want people to think I have something to say worth hearing, not just to talk and be heard. That makes me feel a sense of security. I don't feel secure if people don't believe I can communicate my own thoughts.

--People need to continue to talk to me about everything on an ongoing basis, not just to get an answer. I like people to talk <u>to me</u>, not just to people with me. I want to know the details so always share with me. I don't like it when people talk away from me. Yes I need so much that people realize that communication among all people in my life is the most important thing in my feeling secure.

--When I have something to say, I have to wait to say it. And I need to know that people have got what I have said. So many people don't communicate back to me.

--I would like to know how other people deal with these feelings that come up when they can't express them. What do others do if they don't have S-T or some way of communicating their real thoughts and feelings? It is so frustrating if you can't. In an ideal world, everyone would live with communication assistants for ever at all times. How can Bridges help to get this?

--Be here. Strong, happy friends dream together.

--Sharing ideas is helpful. It's reassuring to know that other autistics feel like me.

--I think it is true this kind of activity helps us connect with others who don't do S-T with us. I think our gathering is calm and I hope people will learn from us. Our Bridges movie should help the cause. Do you agree?

--I think we should support each other with learning together in workshops and courses, and spreading the word like a book.

--We need to train more people to use S-T with us. The movie will help to teach people that we can talk with our letter boards and computers. It will show people we are smart and can think for ourselves. We know what is going on and understand what people are saying.

6 The Bridges-Over-Barriers Dream: Sustaining our Hopes

Supported Typing is very hard. It strains our bodies and minds. But it is all we have. So it is good to do it and we are glad we can. The experiences of meeting with others who type to talk, and sharing our struggles and strategies, gave us the idea of Bridges-Over-Barriers as a name and a vision of a way to help others who have no voices.

The dream, spelled out on the next page, came to me in mid-2005. My Bridges friends liked the idea very much. These are some of the things we might do to realize the dream:

- Make everyone aware that we who do not speak because of movement and communication disorders can be helped to express ourselves, and that Supported Typing (S-T) is real for us.
- Inspire people to respect and listen to us as persons with intelligence and empathy.
- Continue meeting in quiet, calm places where we are accepted and understood.
- Convince those who control our lives that a person who cannot speak with his or her voice deserves the best possible chance to develop other modes of communication, such as S-T.
- Opportunities for children and teenagers who cannot speak to reach appropriate help, but we particularly wish that adults who have no reliable mode of expressing themselves be given a real chance.

Bridges-Over-Barriers Vision (August 2005)

Our gatherings are so important that I want to start a place of refuge and organization for communication and life planning. I want to see more training for people to communicate. I am dreaming of a place where we can come together, to be together, to communicate together. I am dreaming of a place, where I can be a leader and a friend, a person who helps and a person who needs help. . I am really serious about this!

This is really my idea: I want to be in a place where I can greet friends, host meetings, teach about communication and other things that help us. We would welcome people who use Supported Typing and other communication strategies. It is about building bridges, not walls. I want to share this dream, as we have become important to each other in a powerful way. First the Gathering and then the world!

This is how I describe Bridges in asking people to support us: Bridges-Over-Barriers is a centre for friends and family who live with the movement and communication challenges of Autism to come together to share support ideas and community. A group of us has been meeting 9 or 10 times a year from all over southern Ontario. We have been developing our skills as communicators and sharing technology ideas and friendship

I want to tell people that I love Bridges. It gives me a focus and centre of interest, a cause that is important because I believe in myself and my friends. I think the spiritual connection between us is hard to describe. I do think we get ideas from each other. Who knows where it begins, and where it ends?

- Encourage and train more communication assistants who will provide the physical and emotional support that we require.
- Help family members, support workers and friends to feel more confident in being communication assistants.
- Provide resources and training so that we are supported with our communication in all parts of our lives—where we live, where we work, and as we move around the community, in our everyday lives and also as we prepare for good lives and better futures.
- Experience and encouragement to try for more independent typing in which we need little or no physical support.
- Ways for everyone concerned to keep up with the theory and best practice of AAC and S-T.
- Cherish and keep connected with all possible communication allies in all fields so that together we can advocate for various barriers to AAC to be removed or overcome.

Bridges-Over-Barriers has not sought or received any official recognition or funding, and we meet all expenses of the gatherings privately. But friends and family members have given donations since 2005 to launch our advocacy and training efforts. Guelph Services for the Autistic, an organization of which I am an active member, agreed to hold and administer funds in trust for the goals of Bridges-Over-Barriers. Two trustees advise GSA on worthy projects that should be helped. People have been generous and we have already been able to take some steps towards realizing our dream.

These are some ways that we have thought Bridges funds could promote more listening to and respect for people who talk to type:

- Materials and events to increase awareness of Supported Typing and deep listening.
- Information for family members and friends to explain Supported Typing so they know for sure that communicators are expressing their own thoughts.
- Encouragement and assessment of new communicators.
- Training of person-plus-team in Supported Typing.
- Recruiting and training of new communication assistants or partners—individually or in group events.
- More training and experience for those of us who want to become more independent communicators.
- Events, such as workshops or even a conference, to attract all kinds of people who care or are professionally concerned with the why and how of AAC, especially Supported Typing.

All these are steps towards our larger and longer-term dream of "a Bridges centre—a place of refuge where we all belong, a place of organization for communication and life planning."

Our first Bridges grant was made in 2007 to a Toronto man who had recently connected with our group. He was first assessed by a speech-language pathologist, and wanted all his support team in his home to use S-T with him. In a model for others, his application expressed his wish to *"learn how to respond to various communication partners and how to correct if they have said something that I don't mean. I want to learn how to initiate communication and increase my fluency in giving direction, choice making and participating in more complex social exchanges. I'd also like to add my voice to others that are working towards awareness, capacity building and advocacy for people of all abilities and needs."*

The Bridges fund also paid for the sister of another member to attend workshops at the FC Institute, Syracuse University, to help with her goal of supporting her brother in a home of his own.

To increase awareness of our Bridges gatherings and dreams, we started a webpage and a series of bulletins in 2006. The idea of a Bridges video was strengthened when Tim, a founding member, starred in his own video in 2008. We are so fortunate that Christine Zorn, our professional videographer, has been inspired by our dream and has given so much of her time and creative skills to the project. We are confident that our DVD with this book will advance the cause of Bridges-Over-Barriers in all its goals and dreams. We dream of the day when people will be amazed that we were once isolated and excluded because we do not speak.

We may produce future videos and booklets to share techniques and best practices. Another current project is developing technology so that our Bridges members may communicate more efficiently with one another. A Bridges friend who is clever with computers has designed a system for us. We have to be sensitive to the other needs of our members before bringing it into use.

Our foremost goal is that people who cannot speak because of their neuro-motor disabilities should be enabled to express our feelings, thoughts and dreams in our own authentic words. To begin with, and in our more vulnerable times, we need communication assistants who know how to support us physically and emotionally so we can type our words. We always need people with us who believe in our abilities and humanity. Our environments and interactions should be calm, above all, so we can focus on what we want to communicate.

Why/for whom are we making the Bridges movie and book?

- Everyone should know that our lives and thoughts are normal.
- People who don't think we have thoughts of our own, who don't believe in us, to prove we can talk and that we are smart.
- Sceptical and negative thinkers who work with autistic people.
- People who want to learn to use S-T with us, new supporters as well as our parents.
- Our support circles, so they renew their faith in us and try harder to help us improve our lives.
- Bridges members who live far away to help them make new friends.
- We are affected by autism and we need support to talk and to live our everyday life. We want to show people who don't understand that we can talk by typing and listening to each other, and that we are smart. People should know that we are doing the talking--not with our voices but with Supported Typing.
- We have thoughts of our own. I am a good man, smart and can communicate well. I am strong at listening, understanding and being myself. I can do things. I do not like to be talked down to.
- People should know how hard we have to struggle to behave appropriately, as well as about our joy in communicating with others. The world should wake up and accept us as we are. We want to be recognized as intelligent, sensitive and spiritual people who love God and others. We want to be accepted in a faith community where we can be involved and needed. People with autism and disabilities are more in tune with spiritual things because their world is silent and their hearts are open. We need to be allowed to make our own choices and to try new things. People need lifelong education and recreational opportunities.

Once we get going with S-T, technology may help to make it easier for us to type what we mean. It can also help others to hear, record, read, understand and ponder what we say by typing. Most of us who use S-T (formerly FC) started on simple letter boards and depended on our communication assistants to speak the words we type.

As we use S-T more regularly and become more expressive, we or our supporters may get to know of and try electronic devices that may help in various ways. My Bridges friends now use a variety of keyboard displays and we share information and show one another how they work. We have to balance the smart potential of electronic devices with the occasional headaches and stress of making them work well for us. We need technology that is dependable.

From the beginning I have always wanted a device with a voice that I could feel was my voice. So I have used a series of electronic devices, including Epson, LightWriter, Link and DynaWrite which all had voices, as well as AlphaSmart which has no voice. At present I rely most on a laptop running WriteOutloud software, combined with a special keyboard with keyguard and speakers which can be heard in a good-sized room. We sometimes use this for me to chair Bridges gatherings. I also use this or a desktop setup for the independent copy-typing which I use to read and learn about new topics and to prepare myself for change through social stories. This setup has the added advantage of being able easily to record and save what I type. One Bridges member has just started to use an iPad with special keyboard and software.

In addition to the technology of communication devices, we are interested in techniques that could help us to reduce the amount of

physical support we need. One of our group attended workshops at Syracuse University in 2006 and wrote this poem about his joy in finding that it was "not too late". Several members of our group who would like to become a bit less dependent in the amount of physical support they receive have had one workshop in Guelph to begin sharing ideas and confidence. We have viewed and discussed videos of independent communicators.

We will do more to provide opportunities for communicators, facilitators and communication assistants to share their experience and learn from one another in improving techniques to become less dependent on physical support for routine

Not Too Late *by Kevin Vasey, 2006*

Before I went to the summer institute
at Syracuse University,
I was excited and full of hope.
When I got there,
I was happy to see
dozens of people just like me
being accepted, recognized
as important human beings.
Still I was frightened
that nothing important
would come of this.
I had been disappointed
so many times.

They showed me it was
not too late
to learn new things.
Not too late
to learn to talk
even though I am now a man.
Not too late
to learn to type
independently.

Soon I will have a new computer,
small and with a voice,
to take with me everywhere.
I will talk with staff, family and friends
and people in the community.
When I become an independent typer,
others who don't speak
will be encouraged to find a voice.

messages. We could host workshops and also publish guides and manuals about best practices.

Technology can also be used to make our Bridges gatherings smoother and more efficient. Our Bridges friend who is clever with technology is helping us create a system to improve the processes of sharing what we compose with S-T. It would require everyone at a gathering to use laptops linked to a master computer running software to co-ordinate everyone's messages.

These would then be:
(a) spoken by a computer voice to be heard by all,
(b) projected on to a screen or wall for all to see, and
(c) stored in an electronic hansard to share with all who are interested and as a permanent record.

A version of this system could enable us to be connected in a virtual gathering, as well as a real one. The whole system has to work smoothly, without any distractions to disturb our thought processes. Whatever system can be made to work for our needs will also help other people who use AAC to type their thoughts.

Our needs and dreams are big, big, big! Each of us has very individual needs which we can describe using S-T. The kinds of lives we shape for ourselves, understanding our options and making decisions with S-T, must suit our unique personalities, abilities and circumstances. Some of us still have to sort out our priorities and convince the people in our lives that our voices really matter in all choices that affect us. It was only after getting my life in order that I could really think about others.

S-T is awkward, uncomfortable and slow--for us and for the people with whom we interact. But it is all we have—by far our most reliable way of communicating, and very precious to us. Bridges gives us satisfaction and joy to be together and share our ideas and dreams. These thoughts have inspired me, in ending this book this week, to compose a new poem:

Song for Bridges

We are many and we are one:
The bridges that connect us are
our minds and our bodies that
others sometimes find hard to accept.
Together we find acceptance.
Together we find hope.
Together we find community.

We are many and we are one:
The bridges that connect us are
our words and our feelings
though they flow from our fingertips
and not our lips.
Together we find acceptance.
Together we find hope.
Together we find community.

We are many and we are one:
The bridges that connect us are
our family and friends who facilitate
our interactions with each other and the world.
Together we <u>are</u> acceptance.
Together we <u>are</u> hope.
Together we <u>are</u> community.

References

Here we spell out details of some sources we have mentioned, with some notes. We are not providing everything about the form of AAC that we call Supported Typing, or about being autistic and without a voice. These notes are arranged by chapter and in page order.

1 Our Community of Communicators

Bridges has a webpage with more links on the OAARSN website:
http://www.ont-autism.uoguelph.ca/bridges.shtml
Our nine Bridges bulletins are also posted there in PDF.

The Brotherhood of the Wordless is a unique writing collective of fourteen South-East Queensland writers and poets who use FC and have caught the attention of the arts community. The group which meets monthly in Sandgate produced a DVD and book entitled *Tapping on the Heart of the World* in 2005. Various links may be Googled. We also know of another FC users' group, The Lonesome Doves coordinated by William Stillman in Pennsylvania, but there must be more.

2 Recognizing Our Needs to Express Ourselves

pp.24-25 and pp.34-35.
Rosalind Oppenheim, *Effective teaching methods for autistic children* (Springfield, IL: Charles Thomas, 1977).

David Eastham, *Understand: Fifty Memowriter Poems* (1985) and *Forever Friends* (1990, posthumous).

Dr Rosemary Crossley developed the practice and theory of facilitated communication, mainly for people with cerebral palsy, before it became known in North America after 1990. An early notable success was featured in Crossley's book with Anne McDonald, *Annie's Coming Out* (1980), also made into a film in 1984. Crossley published *Speechless* (E.P. Dutton, New York) in 1997. We honour Anne McDonald who died at age 49 in October 2010, just as this book was going to press. Crossley directs the **DEAL Communication Centre** in Victoria, working with people who have Severe Communication Impairment (little or no functional speech). DEAL is dedicated to "Breaking the Silence" and a world in which everyone who cannot speak has the means and the opportunity to communicate." http://www.deal.org.au/
Bridges Bulletin 6 (2008) contains a piece about DEAL, called "Changing the World, one voice at a time."
http://www.ont-autism.uoguelph.ca/BoB-2008-6.pdf
The quotation from Crossley on p. 36 is from a 2008 DEAL bulletin, and is similar to the text at this link:
http://www.deal.org.au/facilitated-communication-training

Jane Remington-Gurney, a speech language pathologist who trained with Crossley, has practiced and taught FCT in Australia for nearly 20 years and has directed the **Options Communication Training and Therapy Centre** since 1998. She is publishing several guides under the general title of *A Slice of My Life,* two of which appeared in 2009.
http://www.optionsctc.com.au/

Douglas Biklen's books include the basic and influential text, *Communication Unbound* (Teachers College Press, New York, 1993). A survey of FC and validation tests is presented in D. Biklen and D.N.

Cardinal, eds, *Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy* (New York: Teachers College Press, Columbia University, 1997). Seven eloquent communicators express themselves in the book *Autism and the Myth of the Person Alone* (edited by D. Biklen, New York University Press, 2005). Biklen founded the Facilitation Communication Institute in 1992, which has offered all sorts of FC training and support to communicators and their supporters from all over North America. In 2010, this has been renamed the **Institute on Communication and Inclusion** with a broader focus. http://soeweb.syr.edu/centers_institutes/institute_communication_inclusion/default.aspx

p. 26: The report of the 1990 survey of Ontario's adults with Autism, *Our Most Vulnerable Citizens: Report of the Adult Task Force* (1991), may be read at this link. http://www.ont-autism.uoguelph.ca/pdf/vulnerable.pdf

pp. 32-34: Communication rights are featured in Bridges-Over-Barriers Bulletin 7 (2007) http://www.ont-autism.uoguelph.ca/BoB-2007-3.pdf

Autism National Committee (AUTCOM)
http://www.autcom.org/index.html

Donnellan, Anne, (1984) "The Criterion of the Least Dangerous Assumption" *Behavioral Disorders*, v9 n2 p141-50 Feb 1984.

National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communication

needs of persons with severe disabilities. ASHA, 34(Suppl. 7), 2–3. Link: http://www.asha.org/NJC/bill_of_rights.htm

TASH: Breaking the Barriers project was a powerful force for the right to communicate: http://www.tash.org/breaking-the-barriers/
Bridges bulletin 5 (2007) contains an article about how TASH advocated for the right to communicate as the basic human right http://www.ont-autism.uoguelph.ca/BoB-2007-3.pdf.

ISAAC: the International Society for Augmentative and Alternative Communication http://www.isaac-online.org/en/home.shtml

Augmentative Communication Community Partnerships CANADA (ACCPC): http://www.accpc.ca/

p. 35: Kevin Vasey and his mother Gloria Pearson-Vasey co-authored *The Road Trip: Life with Autism* (Ottawa: Novalis, 2005).

p. 36: It is encouraging that Dr Pat Mirenda, an influential professional in the field in Canada, has shifted her position on supporting AAC for people with Autism. Proposing what she calls a "back door approach", she thinks *"we need to question what we think we know about people with ASD in general and how we support those individuals whose speech does not develop to communicate through AAC in particular. I think we need to do this because there is a growing body of science that suggests that we might have gotten it wrong, at least some of the time, for some individuals. I think that it is not okay to get it wrong for even one person; when we talk about communication, we are talking about peoples' lives, no less than that – so there really are no degrees of freedom. If we get it wrong, if we miss the boat – people drown."* Mirenda, P., "A Back Door Approach to Autism and AAC". *AAC* Vol 24, Issue 3, September 2008, pp. 220-234.

3 What It's Like to Live with Autism

pp. 40-51: Donnellan, A., Leary, M. & Patterson Robledo, J. (2006). I can't get started: Stress and the role of movement differences in people with autism. In M.G. Baron, J. Groden, G. Groden & L. Lipsitt (Eds.), *Stress and Coping in Autism.* New York: Oxford University Press.

Donnellan, A., Hill, D., & Leary, M. (2010) Rethinking Autism: Implications of sensory and movement differences. *Disability Studies Quarterly*, 30, 1 (17 pages). Special issue on autism and neurodiversity, online at http://www.dsq-sds.org/article/view/1060/1225

p. 51: Broderick, A. & Kasa-Hendrickson, C. (2001). "Say just one word at first": The emergence of reliable speech in a student labeled with autism. *The Journal of the Association for People with Severe Handicaps, 26,* 13-24. [about Jamie Burke]

4 Let's Talk about Our Senses

pp. 53-54: Donna Williams, *Autism and Sensing—the Unlost Instinct* (1998).

pp. 68-71: Lea wrote an account of these ideas and our experiences, quoting from several writers—S.H. Buhner on *The Secret Teachings of Plants* (2004); E. Cowan's *Plant Spirit Medicine* (1995); W. Stillman's *Autism and The God Connection* (2006): and E. Tolle on *A New Earth: Awakening to Your Life's Purpose* (2005). Lea's article, first published in Bridges-Over-Barriers bulletin 8 (September 2009), may be read online at http://www.ont-autism.uoguelph.ca/BoB-8-2009.pdf (pp.7-9).

5 Sharing Struggles and Strategies

For more about Aroha entities of empowerment and support, mentioned pp. 80-93, see Aroha page on OAARSN website: http://www.uoguelph.ca/oaar/aroha.shtml

We are connected with others in Ontario who are working towards direct funding and self-directed planning to enable each vulnerable person to have a better life. More about such creative supports may be found on the OAARSN website at: http://www.uoguelph.ca/oaar/creative.shtml

For more about people with physical disabilities have been empowered to direct their own supports, in what could be a model for us, see *Impact: Changing the Way We View Disability: The history, perspective and vision of the Independent Living Movement in Canada* by John Lord (2010).

The staff of one initiative, Modeling Community Change and Innovation, was interested in Bridges as a group of "self-advocates" who do not speak with our voices but need special support to express ourselves. We were asked questions about supported typing (S-T) as a form of augmentative and alternative communication (AAC), the importance of circles of friends, making our own choices, and individualized funding, and how best others could help us. An article based on this conversation is now posted as "Listening Differently: AAC Users Speak Up About Being Heard" at http://www.ont-autism.uoguelph.ca/Bridge-MCCI-2009.pdf

Bridges bulletin 5 (2008) contains an article "Supported Decision-Making: listening to each one of us." http://www.ont-autism.uoguelph.ca/BoB-2008-5.pdf

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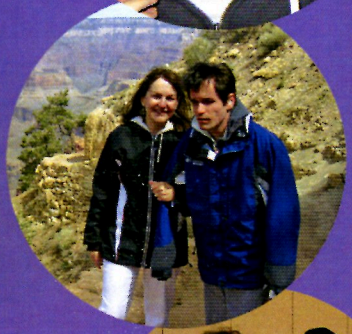
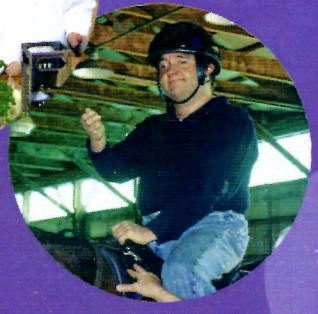
excerpt from video : words of Andrew Bloomfield





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